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WORLD CONGRESS ON FUTURE NURSING SYSTEMS NEW APPROACHES - NEW EVIDENCE FOR 2020

12TH IOS WORLD CONGRESS, MAY 10-13, 2012 LUXEMBOURG

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THE INTERNATIONAL OREM SOCIETY
for Nursing Science and Scholarship
founded 1991

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EDITORIAL

BULLETIN LUXEMBOURGEOIS DES QUESTIONS SOCIALES

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PREFACE

There is evidence that future healthcare systems in general and nursing systems in particular facing major challenges due to access and availability of system specific services. Some of these challenges are related to new and more effective diagnostic procedures and treatment options based on outcomes of groundbreaking research in medical sciences. Increase in chronic illness and changes in awareness of health related quality of life and active ageing will generate new expectations and requirements among healthcare consumers. Healthcare providers need to know the variety and amount of requirements for self-care, dependent care and professional nursing care and the impact this may have on nursing systems in advance. New technologies and indicatory healthcare practices will become influential in the design of future healthcare and nursing systems.

There is evidence that one of the results of these changes will be a faster growing market worldwide. One of the major tasks will be development of institutional and personal abilities to create age-related and self-care oriented programs to help people understand the future demands of healthcare strategies.

In 2012, the 12th biennial IOS World Congress provided a forum for various healthcare and non-healthcare professionals to present and discuss research findings, practice models and practice visions to improve and foster the development for healthcare and nursing care delivery in different societies. The International Orem Society for Nursing Science and Scholarship and the Luxembourg Ministry of Social Security cohosted the congress from May 10 - 13, 2012 in Luxembourg. The event was in particular placed in the context of the '2012 European Year for Active Ageing and Solidarity between Generations'. Keynote speakers and presenters from more than 25 nations were evidence that this years' conference topic, "Future Nursing Systems - New Approaches - New Evidence for 2020", is important around the world.

This publication presents a selection of papers related to a variety of conference topics. All papers have been peer reviewed and were selected by the publication board. In the first section you will find the congress opening speeches followed by an introduction to the Luxembourg system of long-term care in section two. Section three contains the awarded speakers (best poster and best abstract). All other papers will be presented in section four. A reprint of the congress program will be presented at the end of this publication.

As editors of this volume of the "Bulletin luxembourgois des questions sociales" we would like to thank the ALOSS governing board for its preparedness to exclusively devote this volume to the 2012 "World Congress on Future Nursing Systems". We further want to express our gratitude to the generous and very helpful assistance of IGSS to make the congress and this publication happen. The majority of presentations can be downloaded from the congress website: http://www.ioscongress2012.lu and from the IOS website "conferences": http://www.orem-society.com.

Overall, this journal volume is to be seen as a selected reflection of the enormous efforts put in by every presenter and participant of the congress.

Luxembourg, July 2012

Violeta Berbiglia

Jürgen Hohmann

Gerd Bekel

THE INTERNATIONAL OREM SOCIETY
for Nursing Science and Scholarship
founded 1991

MINISTÈRE
DE LA SÉCURITÉ SOCIALE
Inspection générale de la sécurité sociale

12TH IOS WORLD CONGRESS
MAY 10–13, 2012
LUXEMBOURG

Preparing Nursing Systems for 2020
New Approaches – New Evidence

Join your colleagues in contributing to the development of nursing science, particularly the science of self-care, at the 12th World Congress of the International Orem Society. The congress will leave ample room for exchange on international research and scientific analysis on the characteristics, developments and trends in the supply and demand for formal and informal care. We expect around 400-500 delegates from all over the world with the majority coming from Europe.

Message from the President
Building the theoretical basis of nursing is an important contribution that nurses can make to the development of health-related policy and programs.

Kathie Renpenning
President,
International
Orem Society for
Nursing Science
and Scholarship

www.ioscongress2012.lu

Congress languages: English, French, German

Mars Di Bartolomeo
Minister of
Social Security,
Minister of
Health

In the European Year of Active Ageing, Luxembourg welcomes that the IOS, at its 12th World Congress, is bringing the transformation of health and long-term care in our ageing societies to the centre of attention.

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European Year for **Active Ageing**
and **Solidarity between Generations** 2012

Opening Speeches

Mars DI BARTOLOMEO

Minister of Social Security

Dear Mrs. Renpenning, President of the IOS,
Dear speakers and congress participants,
Ladies and Gentlemen,

It is my great honour to welcome you in Luxembourg and Europe, where the European Union and all its Member States are currently celebrating the European Year for Active Ageing and Solidarity between Generations. All over the continent, many activities are being held to create awareness and prepare for the upcoming demographic change in our society. Jointly, we seek to create age-friendly cities and communities with enabling environments for older people, for staying fit and healthy and for having satisfying and autonomous working and living conditions.

When I was asked for the first time in 2010 whether Luxembourg was interested and prepared to host this event in 2012, we were in the middle of preparing our national health care reform. A long-term care system reform was not yet in our focus. But we were already well aware of our need for action to meet the effects and challenges of the ageing population. Due to increasing probability in the population aged over 65 of suffering from more than one chronic disease, we expect a growing demand for more developed and hence more costly health and long-term care systems.

Today our long-term care insurance, implemented in 1999, enjoys very high acceptance. Contributions are mandatory at a rate of 1.4% on all earnings. The constantly expanding capacity and range of specialized care and services have significantly improved access to the system and represent a strong economic factor and a real job motor. Around two thirds of our long-term care recipients receive services at home. Informal care-givers may substitute for some of the professional care services. They are offered particular training, payment and pension contributions. We know that our long-term care benefits are among the crucial factors, why, in Luxembourg, the risk-at-poverty rate among the elderly population nearly is two-thirds below the EU 27 average (6% vs. 18%) (Eurostat 2011). Currently, our expenses for long-term care equal roughly 1.2% of GDP. By 2050 in contrast, according to the OECD, these expenses are expected to increase to 3.1%.

Access to high-quality long-term care definitely requires long-term funding security. And services need to be further developed, and tailored to the people's needs and to the opportunities provided by new technologies. During the last few months, we have undertaken a comprehensive analysis of our long-term care insurance system and its financial model, the final report from which is expected during summer.

Furthermore, in collaboration with the relevant stakeholders, we have developed a cost unit accounting system for nursing homes as a new steering and planning instrument for both nursing home providers and the long-term care insurance fund. It ensures more transparency and enables a direct comparison between financing and output of long-term care performance. The system will be presented and discussed in one of the workshops this Saturday.

In this regard, the time and location of this World Congress on Future Nursing Systems could not have been better selected. For our future long-term care reform, we are absolutely open to inspiration, from you, on new concepts and new approaches in nursing care. I am really pleased about the openness shown from the beginning by the IOS to widen the scope of this congress from the IOS's particular focus on self-care deficit theory in nursing education, practice and research to economic and social issues which are of specific sector relevance, and not only for Luxembourg and the EU.

Topics like ICT, HTA or biomedical ethics, to mention just some, are quite new in nursing care, and we have not yet identified the particular role they will play in our future long-term care design. For Luxembourg, the congress has expressly been approved as a continuing education programme for all health professions.

For the upcoming four days, we are eager to listen to your research results and will relish actively debating them with you. For the end of the congress, I note as a particularly positive sign the willingness of the colleagues from the European Commission and the European Council to meaningfully round off our discussions with their closing and far-sighted speeches on the Europe 2020 strategy and the European Innovative Partnership on Active and Healthy Ageing.

Luxembourg warmly welcomes you, as leading scientists in the field of nursing care, to this congress on evidence in various nursing care approaches. Enjoy the stimulating atmosphere of this congress and its many opportunities to actively shaping the future of our nursing systems. Please don't forget to benefit from the beauty of our country at the same time.

During my term of office, this is already the second opportunity I have had to open, in Luxembourg, an international conference on long-term care. In 2005, within the frame of the Luxembourg presidency of the European Council, we conducted a high-level conference on this issue for the first time. Almost exactly seven years later, by hosting this congress, we are now in the privileged position to be able to observe and actively share the developments in the long-term care sector over the years.

I wish this congress every success.

Kathie RENPENNING

President of the International Orem Society (IOS)

There are challenges facing health care providers which are common worldwide.

- ever increasing requirements for funding of health related programs in an era of economic down-turn
- an aging population the bulk of whom have lived their lives without benefit of the knowledge prevalent today that an active person tends to be a healthier person
- a nursing profession that is young in terms of development of nursing science and the limited development of the theoretical basis of nursing practice
- the lack of integration of nursing science, nursing theories and principles of design in the development of nursing services
- limited practice models which address the broad base of components which are present in every family care-giving situations
- revising nursing education programs to meet current requirements moving the focus of nursing education from the treatment of illnesses to the broader role facilitating management of health related self-care for individuals and their family members.

These topics are all addressed by speakers in this upcoming congress sponsored jointly by the government of Luxembourg and the International Orem Society.

This is the 12th World Congress of the IOS. The society is named for the nursing theorist Dorothea E. Orem. The mission of the society is to advance nursing science and scholarship through the use of Dorothea E. Orem's nursing conceptualizations in nursing education, practice and research.

Self-care deficit nursing theory has gained world-wide recognition as it has been found more and more useful to nursing practice, research, education, and the design and evaluation of nursing services. Previous conferences sponsored by the society have taken place in North America, Europe, Asia, and Africa. In addition, there is evidence of the influence of Orem's work in South America, Central America, and Australia. At each successive conference there has been a more and more diverse representation of papers presented in terms of content and by country. Our interest in having a conference in Luxembourg began at the conference held in South Africa in 2006 during a discussion with Prof. Dr. Olaf Scupin who talked about the policies of the Luxembourg government which supported the relationship between nursing theory and nursing practice.

With this interest already in place it seemed a natural "marriage" that the IOS should join with the Luxembourg government in promoting the theme of active aging by co-hosting a conference which focusses on the science of self-care, self-care deficit nursing theory - a major theory within that science - and the promotion of active aging by facilitating the advancement of self-care throughout the lifespan.

The science of self-care is foundational to nursing practice. One of the major theories within that science is self-care deficit nursing theory. It is a broad general theory of nursing practice, useful in all instances of nursing. It addresses the variables of concern to nursing and their relationships. The theory came about as Orem sought an answer to the question - "Why does a person need a nurse?" Throughout the ages nursing has been viewed by many as secondary to the role of the physician. It has been widely perceived that nurses take care of sick people following the orders of the physician in doing so. But the role of nursing is separate from the physician. Nurses are the largest number of health care providers and as such represent a major component of the health care budget. Much of nursing is "silent" and behind the scenes. It is important to be able to answer the question - why nursing? Why not another health care provider? Why not a family member? It has been established through many studies that the quality and quantity of nursing provided influences both morbidity and mortality rate. So why a nurse? Self-care deficit nursing theory helps to provide for direction in answering that question. Nursing scholars working with Orem by studying instances of nursing action established that nursing is required when persons are to perform the quantity and quality of health self-care for themselves or for family members. Thus they described the proper object of the discipline of nursing - the focus of concern of nurses and were then able to go on and identify the variables associated with that concern.

Understanding the focus of nursing and the variables of concern to nursing has led to understanding the nursing system as an action system which includes actions associated with:

1. The person with requirements for action and capabilities to act.
2. Family members who may have capabilities to act on the persons behalf but also have requirements and capabilities to act on their own behalf.
3. Family members who may have capabilities to act on the persons behalf but also have the requirement and capabilities to act on their own behalf.
4. Nurses with specific knowledge and capabilities to act on behalf of others in health related matters, and with requirements for action and capabilities to act on their own behalf.

The answer to "why a nurse?" has helped organizations in the United States, Canada, Thailand, South Africa. Australia determine whether to hire nurses or some other health care worker and what their role within the interdisciplinary health care environment should be. It has given nursing education programs guidance in structuring curriculum. It has helped to give direction in designing research projects focussing on the interrelationships of variables associated with self-care and with dependent care. With this understanding of the role of nursing within the interdisciplinary health care environment we now have a structure for research, education, and program planning in relation to the provision of nursing services.

Achieving active ageing begins at birth as persons begin to learn self-care through the parenting received, cultural influences, opportunity, trial and error, and so on. By facilitating development of health related self-management and caregiving skills, nurses play a significant role in shifting the focus of health care from the predominant medical model of treating illnesses to a prevention model emphasizing the management of daily life to facilitate healthy living. Continuing development of the science of self-care is foundational to further development of prevention models. Self-care deficit nursing theory has evolved into a major theory within the science.

The decision to hold the congress in Luxembourg appears to have been a wise one. The presenters represent 20 countries - more than has been the case in any previous congress. This provides an opportunity for health care providers in Luxembourg and throughout Europe to exchange a broad perspective of ideas with health care providers and persons interested in the science of self-care from other parts of the world.

It is our goal that at the end of the congress, as a result of furthering understanding of theories associated with the science of self-care and in particular self-care deficit nursing theory, participants will have a better understanding of the place and contribution of nursing within the broader interdisciplinary health care system. We anticipate that participants will have a better understanding of how the science of self-care articulates with other sciences and how nursing articulates with other disciplines to facilitate designing programs which promote self-care, dependent care, and ultimately facilitate active aging. This in turn can result in development of practice models which recognize the variables which influence the exercise of self-care and dependent care. Associated with achieving these outcomes are development of appropriated curricula in schools of nursing and research programs which provide further direction for the practice setting.

Luxembourg Insight

LONG-TERM CARE IN LUXEMBOURG
- A 2012 SNAPSHOT

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ABSTRACT

Luxembourg's social security system is largely based on principles of solidarity, which guarantees generous pension benefits as well as universal access to comprehensive health and long-term care services, and is financed as a pay-as-you-go (PAYG) system with large governmental participation. Policy-making is characterized by consensus and concerted action. The insured population included all people covered by the statutory health and long-term care insurance, including non-resident cross border workers and their dependent relatives and some pensioners. The group of the non-resident insured accounts for up to 30% of all insured.

Before 2009, the country has for some long time not been challenged by major economic constraints such as budget deficits or unemployment. The financial and economic crisis changed this situation drastically and gave an important lesson that even for a small, specialized and open economy like Luxembourg, the strong and continuous growth experienced cannot be taken for granted. It became obvious that partial corrections of the structure of the existing pension, health and long-term care systems are absolutely vital. Since, the social protection system of the country is characterized by a period of transition.

The long-term care insurance, implemented as of 1999 as the youngest branch of the social security system, turned out to be a true blessing for elderly and dependent people as well as for a large number of caregivers. Today, expenditures are rising primarily because of the growing number of beneficiaries and the constantly expanding range of care and services. Trends in long-term care, however, are very much influenced by demographic, behavioral and technical challenges, for which the sharp increase of expenditure is only one indicator, but a very strong one. As a logical consequence, the long-term care insurance and its financial model needs to be thoroughly evaluated and revised. Such a reform is envisaged for 2013, and it remains to be seen what strategies the government will adopt.

By providing an in-depth description of the current long-term care system and its recent developments, this paper aims to increase knowledge about context and reasons that require a greater policy and financing reform in long-term care.

KEYWORDS

active ageing, long-term care, Luxembourg, social security

1 INTRODUCTION TO THE LUXEMBOURG SOCIAL SECURITY SYSTEM

As regards social protection, Luxembourg is currently characterized by a period of transition. From the beginning of the financial crisis it became obvious that partial corrections of the structure of the existing pension, health and long-term care systems are absolutely vital.

The health care sector marked the beginning of this restructuring process as specified by the law of 17 December 2010 on various reform provisions of the health care system. Aiming at better quality of health and flow of precise and valid health information, effective implementation of the law started during 2011 by maintaining a close and trustworthy collaboration with the major stakeholders concerned. Austerity measures, for instance, were designed in a way that the burden had to be shared. The physicians and laboratories had to accept a moratorium as regards the regular mark-up of their tariffs, for hospital care the annual increase of expenditure was determined to a maximum of 3%, and patients were charged with a moderate increase in contributions and co-payments. System innovations and new tools, such as a new function of the family doctor in the form of a (soft) gatekeeper function or the selection of an appropriate national classification for health interventions, as well as the specification of its implementation, were determined in close consultation with the providers. It resulted in one postponed decision or another, but bears the chance of being gainful in the long run.

For the pension reform process that was continuously subject to heavy controversial debate since the announcement of a first immature reform concept in 2010, an important milestone was celebrated by the end of January 2012. The Minister of Social Security not only deposited the pension reform bill at the Chamber of Deputies, but in parallel, a law on the moderate adjustment of the automatic price-index was passed, which postponed the next index tranche, usually due in March 2012, to October 2012, and introduced a minimum space before any subsequent adjustment. In particular the latter provided for a necessary semblance of calm and continuity for an index debate and allowed the partners, contrary to previous attempts, to concentrate the debate on the core measures of the reform concept.

They consist of a moderate adjustment of the pension formula, which foresees a lower replacement rate after 40 years of contribution, but gives room for amplification if the economically active person decides to remain in the labor market until 65. As a cornerstone of the reform bill, the future value of certain parameters will be made conditional on the wealth of the pension fund. Once the balance of current revenues and expenditures turns negative, a scenario that is expected as of 2022, the wage index will be reduced by at least half of the wage increase, the end-of-life allowance will be abolished and, in addition, the contribution rate can be raised with a maximum binding period of 5 years.

In addition to the pension reform, the government negotiated with the employers' association to increase the public subsidies for further education measures from 14.5% to 25% of the expenses per training with the intention that, in return, the employers will keep employees in the workforce for longer.

Apart from the decided harmonization rate of state contributions to both health and long-term care insurance, the latter was so far not subject to any major reform. Already confronted with substantial cost increases, preparation for a reform in 2013 of the youngest branch of the social security system are under way (MSS, 2012, 2).

By providing an in-depth description of the current long-term care system and its recent developments, this paper aims to increase knowledge about context and reasons that require a greater policy and financing reform in long-term care.

The paper is a shortened version of a complete report on the Luxembourg social security system on pension, health and long-term care, which can be found on http.//www.socialprotection.eu.

2 LONG-TERM CARE

2.1 The system's characteristics and reforms

A public long-term care insurance scheme exists as of 1999 as a separate branch of the social security system. Affiliation is mandatory and access to continuous insurance benefits is guaranteed from the first day of membership. Only people covered for long-term benefits by international organisations are excluded, and voluntary health insurance members are restricted for benefit entitlements to a one-year qualifying period. Currently this nursing-care insurance scheme accounts for around 11,700 beneficiaries receiving benefits in kind or cash benefits on a regular basis (IGSS, 2011, 143). The comparatively low percentage of elderly aged 65 and above, a group which in 2009 represented around 10% of the insured population in Luxembourg (OECD average 15%) including 3% aged 80 and over (OECD 4%), once again confirms the country's favorable demographic situation. The number of long-term care recipients accounts for around 13.2 % of this target group above the age of 65 (IGSS, 2011, 144). The latest available figures on public and private long-term care expenditure (according to the joint questionnaire on Social Health Accounts (OECD - Eurostat - WHO)) date back to 2008, where it equaled 1.23% of GDP (http://appsso.eurostat.ec.europa.eu/nui/show.do?dataset=hlth_sha_ltc&lang=en). National data is available only on public long-term care insurance, which in 2010 year amounted to EUR 456.3 million and by then already equaled 1.6% of GDP (IGSS, 2011, 173 and 235). The public expenditure on long-term care includes current expenditure of the long-term care insurance system and those costs for accommodation in nursing homes that are borne by the National Solidarity Fund (accueil gérontologique). By 2050, according to an OECD study, the expenses for long-term care are expected to increase to 3.1% of GDP (Colombo *et al.*, 2011, 74).

Contributions to long-term care insurance have to be paid at a rate of 1.4% on all earnings (including fringe benefits and capital) without any upper threshold. This unique feature remains in contrast to the other social security branches (pension, health), where the contributable income is limited to five times the minimum salary. From 2006-2011, the state contribution to the long-term care insurance fund was fixed to a nominal amount of EUR 140 million. Initially, this part represented 45% of total revenue, but has constantly been reduced to only 33% in 2010. The amount equals the state contribution from 2006, when it still represented 45% of total revenue (IGSS, 2011, 174). A smaller additional source of revenue comes from a special earmarked electricity tax for high-volume electricity consumption. By Article 38 of the law of 16 December 2011, the government put an end to these differences in state contribution between health and long-term care insurance and adjusted the provisions of the relevant article 375 of the Social Security Code to a level to 40% of all expenses. The measure, however, will only become effective as of 2013. For 2012 as a derogation to the new provision, the state contribution was fixed at 35% of expenses (Law of 16 December 2011 on the state budget 2012, Memorial A-266, 4380; MS/MSS, 2011, 8).

Despite relatively higher social security contributions, long-term care insurance still enjoys a high degree of acceptance among the population. One of the reasons might be the generous benefit package for long-term care that is offered without almost any co-payment. In 2011, a small participation of 12% was introduced for medical services provided by nurses during home care and in institutions. They only represent a minor range of the long-term care services and are covered by health insurance (and not by long-term care insurance) (http://www.chd.lu/wps/portal/public/RoleEtendu). The provision is to a large extent offered in kind by a specialized, well-organized and labor-intensive service sector. In 2009, roughly 9,500 persons (7,100 full time equivalents) were employed by the providers for home care and institutional care (IGSS, 2011, 141). It represents around 3% of the national labor force and is dominated by females. In 2009, the previously experienced rapid annual increase of employment of more than 5% started to slow down for the first time (+2.9%). In addition, a total of 4,800 persons are registered as informal caregivers to partly replace the professional caregivers for up to maximum 10.5 hours per week.

Market entry to the care-giving sector is restricted to organisations approved by the Ministry of Family Affairs based on the fulfilment of certain quality standards and after adhesion to a framework contract with the long-term insurance organisation, which determines the rights and obligations for executing the nursing care services.

The sector acknowledges four types of service. In 2010, there were

- 15 ambulatory networks for home care with two dominating institutions (Stëftung Hëllef Doheem, Help),
- 50 day care institutions,
- 37 intermittent care centres (for alternating short-term stays according to the actual level of dependence),
- 52 nursing homes and integrated homes for the elderly with a capacity of 5,154 beds in 2010 (48.8 per 1,000 population above the age of 65) (IGSS, 2011, 139 and OECD ECO-Health Data 2011).

Whether or not and to what extent a person is eligible to receive long-term care benefits depends on an individual assessment of dependency status by the *Cellule d'évaluation et d'orientation* (CEO), the competent public organization for this task under the responsibility of the Ministry of Social Security. In 2010, the organization received around 4,700 requests to classify or reclassify the individual need for nursing care services. Another 8,000 applications concerned (minor) technical aids and housing adaptations, likewise covered by the long-term care insurance.

The system allows many people in need of assistance with their personal care to remain in their home environment. Indeed, the majority of long-term care recipients receive the services at home (67%) (IGSS 2011, 145; Colombo, 2011, 40 and OECD Key Facts Luxembourg). It is also possible to (partly) replace the benefits-in-kind provided by a professional organization through an informal caregiver, but limited to a maximum of 10.5 hours per week. In this case, the long-term care insurance grants the care recipient a cash benefit of EUR 25 per hour in order to pay for the informal caregiver, takes over the costs for counseling of the informal caregiver and also pays the latter's pension fund contribution (Art. 171 and 354 of the Social Security Code (CSS)). In 2009, the pension fund contribution accounted for a total of EUR 4.5 million, which in comparison to 2009 represented an increase of 10% (MSS, 2012, 36). 66% of home care recipients opt for this voluntary combination of professional and informal caregivers (Colombo, 2011; OECD Key Facts Luxembourg). The majority of the latter are (female) family members (Fleury *and* Lorentz, 2011). Occasionally the services might also be provided or augmented by illegal caregivers. This phenomenon, however, is not the subject of any public debate.

Institutional care is provided in nursing homes and integrated centres for the elderly (CIPA). Around one third of residents in the latter are elderly people who are not dependent on nursing care services (Gantenbein, 2011, 2). In 2008, this last area employed 60% of the sector's workforce. The staffing level with a caregiver-to-resident ratio of 1:1.88 is well beyond the norm of other EU Member states (Luxemburger Wort, 2011). In comparison, for the German federal state of Saarland, the article reports a caregiver-to-resident ratio between 1:2.07 and 1:3.92 according to the level of care-dependency (measured in three classes).The providers are remunerated by the long-term care insurance scheme according to a sector-specific fee per hour (*valeur monétaire*), which is negotiated between the long-term care insurance and COPAS, the representative association for nursing homes and integrated homes for the elderly and was set at EUR 46 for 2012 (COPAS, 2012, 6). In the year 2010, the average costs per resident were EUR 4,662 in CIPAs and EUR 5,454 in nursing homes, which does not include the costs for board and lodging that have to be paid by residents themselves (Gantenbein 2011, 2).

A law on palliative care entered into force in July 2009. Although the services are financed by the long-term care insurance, according to the procedures, it is the Medical Control Service of the Social Security (CMSS), usually in charge of assessing the lawful utilisation of health insurance benefits, which authorises or denies palliative services (Art. 351, No. 2 CSS). However, benefits of the long-term care insurance can be provided in addition to palliative care services (Art. 349, No. 4 CSS), because essential benefits are not simultaneously on the list of palliative services. Complementary training programs for palliative care are offered for professionals in the health and long-term care sector to become acquainted with these particular circumstances.

The long-term care insurance scheme delivers a solid foundation for keeping the care of the elderly on a secure footing and has created the above-described prosperous economic sector and labor market for home and inpatient care. These strengths also have their costs. Between 2008 and 2010 the costs of long-term care insurance rose on average by 12.2% annually compared to an annual 5% increase in the number of beneficiaries during the same period (IGSS, 2011, 143 and 173). The consequences of such precarious development are not unknown. An earlier deficit period between 2004 and 2006 was finally remedied in 2007 by a substantial increase of 40% in the individual contribution rate (from 1 to 1.4% of gross salary) and brought about an annual reserve of 8-11% of total revenues (IGSS, 2011, 173; MSS 2011, 44). Only two years later, the current expenses once again almost equaled the current revenues and will tend to substantially surpass them in the future. Thus, further adjustments will be unavoidable.

Over the last years, long-term care insurance was not subject to any major reform. Despite the financial crisis, its financing situation is still basically stable, which has enabled the government to concentrate on major reforms of the health and pension system. Within the sector, the actors used this period of tranquillity to gain transparency through the mutual development of a unified analytical accounting system (*Kostenträgerrechnung*), the application of which is mandatory as of 2011 for all institutional care establishments, and through some administrative restructurings of the CEO to substantially improve the procedures as regards the individual assessment of the dependency status of an applicant for long-term care services (MSS, 2012, 52-63).

2.2 Debates and political discourse

The crucial criterion for entitlement to the benefits is proven dependency on assistance from a third person for the activities of daily living (ADL) for a minimum of 3.5 hours per week, which is expected to be indefinite. As described above, the CEO determines the number of hours individually on a continuous scale, unlike certain case stages as applied in some neighbouring countries (Colombo, 2011, OECD Key Facts Luxembourg). In 2010, a long-term care beneficiary received weekly on average 34.3 hours of care provision. For 18% of the recipients, services were even granted for more than 9 hours a day (> 64 hours per week) (IGSS, 2011, 153). Even below the 3.5 hours minimum threshold, there is still a possibility of receiving means-tested financial assistance from the National Solidarity Fund to pay for the services.

2.2.1 Reimbursement rules for domestic services

In addition to nursing services, allowances for domestic services can be added. With the exemption for some extremely dependent persons, they amount to 2.5 hours for home care. Within institutions, this allowance was subject to a controversial debate between providers and the long-term care insurance, which finally resulted in development of a unified analytical accounting system (*Kostenträgerrechnung*) over several years. In the future, these domestic allocations in the framework of institutional care will be determined in terms of the specific extra workload for care-dependent residents in excess of the workload for non-dependent residents. It will be applied in form of two flat rates, expressed in weekly hours per person. One represents the directly attributable extra effort per dependent resident (i.e. cleaning and tidying up of the room) and one the extra effort that is only indirectly linked to an individual resident (i.e. cleaning of common rooms, food tray preparation, distribution and collection). The exact amount will be determined by the respective results of self-evaluations conducted three times per year in all long-term care institutions, covering all services provided by employees and service providers. As of 2010, the extensive self-recording on all services rendered by all nursing-home employees and contracted service providers takes place three times a year over a 48-hour period. Due to the lack of meaningful baseline data, for a transitional period until 2012 the law applies two flat rates, which reflect the same volume as applied for the home care sector (Art. 357, No. 2 CSS).

2.2.2 Price for accommodation

In inpatient nursing homes or homes for the elderly, the price for accommodation (including board, lodging, basic domestic services, laundry, etc.) is individually determined by each establishment and has to be paid by the resident himself. Despite the remuneration of all services related directly to care provision by either the health insurance or the long-term care insurance, the price of accommodation remains quite high. Unfortunately, there is no publicly available comparable information of the accommodation price per institution. In its latest practical guide for senior citizens, the Ministry of Family and Integration only publishes the monthly minimum rate for a bed in a double room of EUR 1,548 in 2010 (MiFa, 2011, 78). As an example, a newspaper article from February 2011 compares the accommodation prices of two institutions of the one provider (Zitha Group), which range from EUR 1,637 to EUR 2,483 (Lepage, 2011, 2). And the Hospices Civils of the City of Luxembourg, to mention another, raised the price for a single accommodation in 2012 (EUR 2,467) by 17% in relation to the previous year (http://www.hcvl.lu/FR/forfaits.html).

The National Solidarity Fund provides mean-tested support of these costs (*accueil gérontologique*). In 2010, approximately 700 people received on average EUR 864 per month. This amount, however, represents an increase of 7.4% in only one year, for which the increase of the accommodation price is given as sole explanation (IGSS, 2011, 233-235). Therefore, a comparable and transparent accommodation-price scale of all institutions is considered absolutely vital.

2.3 Impact of EU social policies on the national level

In the European Union, there is a general awareness that long-term care systems needs are going to increase in the future. Long-term care arrangements are characterised by a low degree of institutionalised structures in particular in new Members States, while South European countries depend to a high degree on informal care by family members or migrant workers. An overall priority to provide support for home care as opposed to institutional care can be observed. There are various measures to foster home care, e.g. financial allowances to purchase private support, labour market regulations which allow a temporary reduction of working hours for relatives, and publicly financed social services to enable a person in need of long-term care to stay as long as possible at home.

Financing approaches in long-term care vary substantially across European countries. Often, public financing is provided by a fee-for-service or a fee-for-person. In some countries, co-payments for institutional care are dependent on income, sometimes income of first-grade relatives is also taken into account. There are countries where long-term care benefits are fully means-tested. Others cover the cost of care services, while board and lodging has to be paid by the resident himself/herself.

Apart from Luxembourg, only few European countries have established a social insurance scheme to cover long-term care risks (Germany, the Netherlands). In some other countries, such public mandatory insurance scheme has been discussed recently. Finally, in Poland and France, they have largely been rejected, assuming that they are too costly. In Slovenia, to mention another example, a proposal to introduce a long-term care insurance is under discussion since 2005 (Horstmann, 2011, 17-21).

Quality standards, in particular in home care, are an issue in many countries, and improving the quality of long-term care services is a key concern. Decentralised long-term care systems have often resulted in substantial disparities with regard to the quality of care. The introduction of nationwide unified assessment instruments appears to be of key importance in providing access to quality care and fostering the efficient use of financial resources.

Against this background, it surprises that long-term care was an absolutely neglected issue in new cross-country coordination instruments, such the EU Annual Growth Survey (AGS) from January 2011 and its annexes (European Commission 2011). For the Annual Growth Survey 2012, despite having slightly improved through a very brief mention of its role for employment and the protection of the vulnerable, it still remains insufficient (European Commission, 2011a, Vol. 1, 10-11; Vol. 2, 18; Vol. 4, 11).

This is surprising insofar as the nursing care industry has long represented a prosperous and labour-intensive economic sector with a high proportion of female employment IUIL, 2011; Colombo *et al.*, 2011, 77). The number of professionals in the long-term care sector (expressed in full-time equivalents) has increased since 2005, on average, by more than 5% per year (whereas between 2008 and 2009 the growth rate fell for the first time below 3% (IGSS, 2011, 141). As such, the sector contributes by and large to the headline targets concerning national employment and economic growth and is in the focus of the 2012 European Year of Active Ageing.

Disregard of the long-term care sector in both the National Reform Program (NRP) 2012 and the "13th Update of the Luxembourg Stability and Growth Program" may reflect the low value attached to it by the AGS 2012 as well as the Ministry of Economy as regards the Open Method of Coordination (OMC) and the EU 2020 strategy (European Commission, 2011a; Government of the Grand-Duchy of Luxembourg 2012a). Against its current focus on life science research as the sole mentioned branch of health care (Government of the Grand-Duchy of Luxembourg, 2012, 31-32), the quality of the NRP 2012 could be much enhanced by the addition of various strategies on how health and nursing sciences can gainfully complement the heavily subsidized life science industry. The Luxembourg cluster programme, for instance, which is presented in the same chapter (Government of the Grand-Duchy of Luxembourg, 2012, chapter 5.2.2), targets health, long-term care and active ageing in dedicated working groups extending beyond biohealth research (http://www.ictcluster.lu). Only the National Social Report (NSR) 2012 includes an interesting two-page overview on the health-care reform as well as a short but unfortunately not very meaningful chapter on long-term care. The latter neither outlines the system's great economic and labour market achievements nor does it describe interesting recent studies and their potential impact on the upcoming reform of long-term care insurance (Government of the Grand-Duchy of Luxembourg, 2012b, 11).

The atypical composition of the social security membership with a share of above 30% of cross-border workers makes Regulation 883/2004/EC of the utmost relevance. Therefore, Luxembourg is especially exposed to all the challenges that long-term care coordination brings (Jorens *et al.*, 2011). Though the issue has been of minor importance until now, the comparatively huge benefits granted by the Luxembourg long-term care insurance will sooner or later lead to increasing demand by future immigrants.

With regard to the risk of impoverishment, Luxembourg pensioners are in a very favourable situation. In 2009, the at-risk-of-poverty rate for the population of 65+, at only 6%, was on the EU baseline and nearly two thirds below the EU 27 average (17.8%). They only show minor deviation from the prospects for 2010 (Luxembourg 5.9% vs. EU27 15.9%). For the population of 75+ the situation is quite similar (Lux 5.3 vs. EU27 20% in 2009). The situation is surprising in that the risk of impoverishment for the elderly is less than 40% as high as the average for the country's population below 65 (15.8% in 2010). Equally contrary to the general development in Luxembourg, the risk of poverty among the elderly has even decreased since 2003.

This comfortable economic situation for the elderly may be explained by the following factors:

- Generous pension benefits, including minimum pensions, which grant at least 90% of the minimum salary for a full pension career.
- Compulsory membership of the social security system that avoids penalising the self-employed, people with interrupted careers and other insecurities.
- A guaranteed minimum income of monthly EUR 1,283 in 2012 and a yearly tax credit of EUR 300 equally apply to the elderly.
- Long-term care insurance grants generous long-term care benefits with almost no co-payments.
- The elderly spend a relative low share of disposable income on housing, as roughly 85% of the population aged 65 or over are owner-occupiers (Zahlen, 2011, 2).
- A particular situation of migration with a high share of non-national residents (43% in 2010) (Statec, 2011) does not apply to the elderly (only 15%). The fact that migrant workers have both shorter careers in Luxembourg and, on average, less income than the autochthonous resident population, may lead to the assumption that those who return in old age to their home countries receive pensions below the average of the resident pensioner population (Schronen and Urbé 2011, 282). This phenomenon further reduces the number at risk of poverty among the elderly.

This list indicates that the generous long-term care benefits, granted without any co-payment, are among the crucial factors for this favourable situation of the elderly in Luxembourg. Admittedly, the price for accommodation in a nursing home is quite high and has to be paid by the resident himself. As explained above, the National Solidarity Fund provides mean-tested support of these costs for the dependent elderly with a low income (*accueil gérontologique*). In Luxembourg, roughly 85% of the population aged 65 or over are owner-occupiers. Consequently, the costs for housing represent a much lower share of disposable income than in other countries. For recipients of home care, the pecuniary advantages for the elderly are even more striking. The fact that roughly 85% of the population aged 65 or over are owner-occupiers reduces the costs to be spent on housing considerably (Zahlen, 2011, 2).

However, a situation in which the younger and active population, already today, is faced with a much higher risk of poverty is alarming information itself. Indeed, the state is also obliged to respond adequately to the needs of other population groups apart from the elderly, such as the young, migrants, and single parents, but also to other human requirements, like satisfactory housing, transport and education (Schronen *and* Urbé 2011, 288).

2.4 Impact assessment

Trends in long-term care are very much influenced by demographic, behavioral and technical challenges. Thanks to the effect of immigration, Luxembourg still enjoys a relatively moderate old-age dependency ratio in comparison to other EU countries, with a proportion of older people aged 65+ in relation to the number of persons of working age (from 15 to 64) of 20% in 2010 (EU27 = 26%) (Eurostat, 2011, Old-age dependency ratio (tsdde 510)).1) The ratio is expected to rise to 30% (LU) and 38% (EU27) in 2030, and to 45% (LU) and 53% (EU27) respectively in 2060 (Eurostat 2011, Projected old-age dependency ratio (tsdde511)). It will have major implications on the demand for long-term care in general, but also on the range and main emphases of long-term care provision.

In 2010, about 13.2% of the population above 65+ was registered as a beneficiary of the long-term care insurance (IGSS, 2011, 144). The probability of suffering from more than one chronic disease increases significantly in the population aged over 65. Especially dementia is expected to increase substantially. In 2010, it already represented 30% of the primary cause of long-term care dependency of people at the age of 80+ (IGSS, 2011, 151). In the medium term, increasing demand for more developed and hence more costly health and long-term care services will bring the system under further financial pressure. A market analysis from 2010 came to the conclusion that

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1) *This indicator must not be confused with the ratio of elderly people to the overall insured population, which represents only around 10% for the same year.*

by 2015, the country will need 1,400 to 2,100 beds for long-term care in addition to the 5,000 that already exist, and estimated the demand for investment in new nursing homes at between EUR 230 and 480 million (Ernst &Young, 2010). It will also imply a growing shortage of qualified nursing staff, as even today, the labor market faces difficulties in meeting the specific demand (IUIL, 2011, 30-32).

In March 2011, a Working Group "ICT for a healthy and ageing population" of the Luxembourg ICT Cluster was launched. Together they exchange know-how and experience and foster collaborative projects on a national as well as on an international level to enhance independent living and improve the quality of life of elderly and disabled people (http://www.ictcluster.lu/Cluster-Working-Groups/ICT-for-a-healthy-and-ageing-population). The group is composed of representatives from companies, public research, health care and other stakeholders. Very surprisingly, the long-term care insurance does not participate in the working group of the cluster.

It is important to know that the two largest home care providers, *Hëllef doheem* and *Help*, are very active members of the cluster. In 2005, they introduced for the first time smart housing elements in form of movement, smoke or gas detection. In 2010, the service counted 4,300 active clients, of which 91% were above 70 years (MiFa 2011a, 266). This further developed into virtual sensor technology, able to link up to 40 individual sensors, which are available as of 2012 (http://www.shd.lu/ and http://www.help.lu).

One of the cluster's research partners, the national public research center CRP Tudor, developed telemonitoring devices for congestive heart failure, one of the leading causes of hospital admission in the population aged over 65, and brought them to market maturity (www.santec.lu/project and http://www.monitor-it.lu/). The center furthermore conducted a randomized clinical trial to compare a group of home-monitored patients to a group of conventionally treated patients in order to analyze the effects of the device on quality of life, re-admission rates and health care costs in general (http://www.santec.lu/project/luhf). Another ICT product and related scientific impact analysis concerns the management of food allergies through a mobile expert and networking device helping to distinguish permitted and non-permitted food (http://www.santec.lu/project/menssana). Other members are the Luxembourg based company Actimage, which is involved in eHealth projects on managing insulin for diabetic patients in real time (Actelin) or in international ambient assisted living (AAL) research program on the development on a mental wellness toolset (http://ww.actimage.net).

2.4.1 Applied research focuses on quality improvements

The quality commission on long-term care is responsible for defining the norms and quality standards of the long-term care services that are provided on behalf of the long-term care insurance. A system to regularly monitor the quality of services and advise the providers on constant improvement is under development (MSS, 2012, 60). Art. 361 of the Social Security Code mandates the quality commission to additionally pilot certain quality-enhancing activities. These activities are subject to scientific monitoring and evaluation. During the reporting period the following pilot and research activities were conducted:

- The project "Night watch" was carried out as of March 2009 for a period of two years. It aimed at developing and evaluating the concept, demand and costs of professional night watch services, for which demand was initially estimated at 350 persons. Finally, only 50 people benefitted from the pilot night watch services. One concluding assumption that the demand for these services was largely over-estimated can be rebutted by the fact that another 120 people made use of the services on their own expenses. These persons did not reach the eligibility criteria of a severe dependency status, despite in majority they are suffering from dementia and other serious illnesses. Thus, the eligibility criteria were equally called into question. Since the end of the pilot project, the Ministry of Family and Integration (MiFa) covers the costs for the night watch services, until a final decision on their inclusion into the long-term care insurance package will be made (MSS, 2012, 60).
- In November 2011, a patient satisfaction study, conducted by the national research centre CRP Santé between August 2009 and July 2010 was presented. The study was commissioned by the Cellule d'Evaluation and Orientation (CEO) and followed a comparable study from 2006 on home care. In general, the results show a high degree of satisfaction by the interrogated nursing home residents. Despite the fact that the atmosphere of the particular nursing homes, and an impression of feeling at home got relatively high scores, only 63% were willing to recommend their institution to others. Critical comments concerned, for instance, the lack of time for a personal conversation with the personnel or a lack of trust in a number of care-givers Lair *et al.*, 2011; MS/MSS, 2011, 5-7).

2.4.2 Development of a sector-wide cost unit accounting system (Kostenträgerrechnung)

The preparation and introduction of this analytical accounting system represents the most far-reaching innovation of the long-term care sector. The Ministries of Social Security and Family Affairs commissioned this relatively complex development as a steering and planning instrument for the sector of institutional care (nursing homes and integrated centres for elderly) in order to better cope with the new challenges of long-term care. After three years, the development was completed by July 2011. Results of the first comparable data set will be available as of the fall of 2012.

As to its methodology, the approach pursues a transparent allocation of care provisions and costs to certain performance categories (basic nursing care, treatment care, domestic services, etc.) and type of residents (beneficiary or not of benefits covered by the long-term care insurance). Thus, it aims to enable a direct comparison between the financing and output of long-term care performance. Although based on sector-wide average values as the main orientation of comparison, individual specifics of infrastructure, composition and care-dependence of residents as well as care concept are taken appropriately into account.

After the successful completion of a pilot study in 2009, all stakeholders together (including representatives of the association of long-term care institutions COPAS), made the unified analytical accounting system ready for its unified sector-wide implementation and its continuous further development. It required separate development of the following three areas, which were later reassembled. A fourth area is concerned with the financing of domestic services in nursing homes.

- **Standard form of accounts:** The existing accounting charts have to be harmonized to be integrated into the accounting systems of all nursing homes. Furthermore, the allocation logic of types of costs (personal costs, real estate costs, etc.) to costs centers (administration, care services, canteen, etc.) had to be developed mutually. The interference with a parallel new government project to prepare for a standardized chart of accounts for all economic sectors, represented by far the biggest challenge but, due to the postponement of the latter, finally only played a tangential role.
- **Collection of performance data:** A comprehensive and scientifically validated questionnaire was developed, to be used for collecting all services rendered by all nursing homes. Data-collection is performed in the form of an anonymized exhaustive self-recording approach, conducted by all active employees and service providers of one nursing care establishment within the collection period. As of May 2010 the collection recurrently takes place on six days a year (3 times 2 consecutive days per institution). Details on the collection methods were described in a handbook and a training-of-trainers concept was implemented. The completed questionnaires are run through a particular scanning procedure in order to permit statistical analysis.

- **Data conflation into a cost unit accounting system (*Kostenträgerrechnung*):** The cost unit accounting system requires an unambiguous allocation of financial and performance data to the pre-identified performance complexes and types of recipients. All individual distribution keys were determined by a participatory decision-making process among all relevant stakeholders. The latter made the cost unit accounting system quite lengthy and costly, but at the same time constitutes an effective measure towards far-reaching acceptance.

Preparation for a long-term care reform

During the reporting period, the government priorities were clearly laid on the reforms of the health and pension insurance system. A comprehensive report on long-term care is in preparation and expected for the second half of 2012. On the one hand, it will describe the historical development and status quo of the current system. On the other, it is expected to lay the foundation for a major reform of the long-term care sector as of 2013 at the earliest.

3 THE ROLE OF SOCIAL PROTECTION IN PROMOTING ACTIVE AGEING

3.1 Employment

Today, incentives for working longer than 40 years of a pension insurance career do not exist, and the disincentive for not completing the 40 years is cushioned by the high minimum pension rate. The new pension reform plan only marginally promotes a longer working life. It foresees a lower replacement rate after 40 years of contribution, but leaves room for amplification if the economically active person decides to remain in the labour market until the age of 65. Furthermore, supplementary (self-) employment during retirement is planned to be simplified. These, and other measures presented previously seek to increase the retirement age. The approach can be considered a soft one. Unequal opportunities, such as working conditions and health status do not play a role in the discussion. The current status as well as the reform plans do not set out a mandatory requirement age. Envisaged, however, is a retirement age of 65.

3.2 Participation in society

Baby-years are also credited as insured time of the pension system, counting as qualifying periods, with two years for one and four years for four children. Pensionable earnings are based on pay immediately before the baby years. Employees who could not claim baby-years due to an insufficient contribution period have the right to a special monthly allowance in retirement, the so-called "Mammarent", of EUR 87 per child per year (http://www.guichet.public.lu/fr/citoyens/sante-social/assurance-pension/pension-vieillesse/demander-forfait-education/index.html).

Further, a possibility exists to contribute voluntarily to the pension system, either in order to guarantee a continuing contribution to the assurance or to fulfil all insurance periods. The minimum contribution equals 239.61 EUR per month (http://www.cnap.lu/fileadmin/file/cnap/assurance/Demande_pension_continuee_instructions.pdf#pageMode=bookmarks). The new reform proposal foresees a reduction of the contribution to 100 EUR. The following example represents one option of the target group.

The care of a dependent person can be credited as contributory period under certain circumstances. Firstly, the dependency of a person needs to be approved by the long-term care insurance. Secondly, if the informal caregiver does not benefit from a personal pension, the dependent person can claim for him/her to have the pension contribution insurance paid by the long term care insurance. The dependent person can further claim cash benefits for the informal caregiver.

3.3 Healthy and autonomous living

There is a clear political priority to provide support for home care as opposed to institutional care. As described above, the benefit package of the long-term care insurance is very generous and does not involve any co-payment. Informal caregivers can partly replace the professional caregivers for a maximum of 10.5 hours per week. Ambulatory networks for home care, day care institutions as well as intermittent care centers can provide help for the dependent person. Further, nursing homes and integrated homes for the elderly exist. The political preference for home care can be confirmed by the fact that two thirds of the beneficiaries of long-term care insurance receive their nursing services at home.

In Luxembourg, the so-called Club Seniors, organized and managed by the Ministry for Family Affairs and Integration, provide plenty of opportunities for people aged 50 and older to stay active and involved. They further advance social integration and participation, and support the prevention of physical and mental deficiencies. Each of the 16 club offers a variety of activities, such as yoga, language course, handicraft courses, and computer courses. A number of other organizations support the voluntary work of the elderly.

Various associations further support the independent living of the elderly, such as help lines for questions regarding activities, care, consultation etc.

4 CONCLUSION

Since its implementation in 1999, the long-term care insurance scheme has led to a substantial change in the market for long-term care provision. Expenditures are rising primarily because of the growing number of beneficiaries and the constantly expanding range of care and services. The capacity of specialized home care services and the number of beds in nursing homes and CIPAs have admittedly improved access to the system, but also weakened the originally good financial situation of the long-term care insurance scheme.

Therefore, the government's impetus to foster quality improvements, enhance standardization, strengthen technical progress and master system inefficiencies can only be acknowledged. Especially those projects which aim at bringing transparency and performance standards to the system seem to appropriately serve the political requirements for better steering of the sector. The implementation of more effective and transparent procedures to assess dependency status and evaluate the volume and specificity of the support needed also help to increase people's faith in the administrative system. However, there is still room to improve the information on service quality and the relevant prices of nursing home accommodation.

The system-wide unified analytical accounting system, which over the last three years was meticulously developed by the responsible Ministries of Social Security and of Family and Integration in close collaboration with COPAS, CEO and CNS, is now in its critical phase of implementation. During its development, the attention was laid on a laudable, but time-consuming, participatory decision-making process, through which all individual distribution keys were determined on the basis of a joint agreement. For a successful long-lasting implementation, however, it is the system's legal base which will be challenged by its opponents. Only rigorous application of the developed instruments will finally bring the reliable data necessary for greater transparency, which the cost unit accounting system was intended to deliver from the beginning. This database could also serve Luxembourg as an important source for an evidence-based study on long-term care.

The phenomenon of medically intended absence from work of pregnant women, often as of the day the pregnancy becomes confirmed, has a delicate and serious negative impact on the female-dominated labor market in long-term care. Human resources management in the long-term care business becomes extremely difficult as a consequence. This internationally exceptionally generous protection of pregnant women seems to be granted to the detriment of the quality of services for elderly dependent persons and society as a whole. It is just inconceivable that this labor-intensive sector could be unable to allocate physically less demanding tasks to pregnant women and to keep them as long as possible as important reference persons for the dependent elderly.

From today's perspective, the long-term care insurance system is a true blessing for elderly and dependent people as well as for a large number of caregivers. It can only be hoped that it can keep up its momentum, increase the service quality and stabilize its financial basis. Even though the nursing care services are quite domestically orientated, any research and actions taken that bring and keep Luxembourg's nursing care services at a top level of quality and cost-efficiency by international standards should be welcomed. Furthermore, the comfortable financial situation of many elderly people in comparison to the general public would allow the introduction of co-payments for people above a certain pension income as well as in possession of sufficient financial and property assets without jeopardizing the solidarity paradigm of the long-term care insurance.

In the very near future, the ageing of the population will unavoidably lead to further increases in the demand for long-term care infrastructure and services. As a logical consequence, the long-term care insurance scheme and its financial model need to be thoroughly evaluated and revised. Given the economic importance of this area of social security, it is quite astonishing that the long-term insurance scheme does not play any active role in research on ICT in nursing care environments, which is expected to provide the largest impetus for transformation in this field of activity.

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Keynote Speakers

MOVING FORWARD:
RAMBLINGS OF A GENUINE ANTIQUE NURSE

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KEYWORDS

nursing education, nursing practice, nursing science, nursing theory, self-care science

1 INTRODUCTION

There is an ever increasing demand for professionally educated nurses. In the future, major areas of practice will involve helping persons learn how to care for self, requiring knowledge of the science of self-care, as well as providing care, requiring sciences of nursing action/caring. The general theory of nursing, Self-Care Deficit Nursing Theory, is the essential structure for nursing (Orem, 2001). The increasing number of people with chronic diseases and increasing use of technology requires nurses with not only theoretical knowledge of the science of self-care but also design and technological skills. Future roles of professional nurses need to be developed in light of these variables. A solid science base balanced with a commitment to personalism (Taylor & Renpenning, 2011) is essential for professional education and practice.

This overview of the world of nursing from my perspective is organized around three time points - obviously the past, present and future. While we know events of the past, we are still interpreting their meaning and effect so as to aid us as we move forward into the future. Remember that my perspective is reflective of the United States (U.S.), though I think other cultures mirror our experiences to a great extent.

2 PAST

I began my career in nursing over 55 years ago. As with so much in this world, there have been phenomenal changes in how we educate nurses and how we provide service to patients. In 1957, when I graduated from a degree program, the majority of nurses were being educated in hospital-based schools of nursing. I was fortunate to attend a liberal arts college, receiving a baccalaureate degree in nursing with good science and liberal arts in the curriculum along with an extensive base of clinical education - much more than is found in the typical program today. Two year associate degree technical nursing programs didn't exist. Vocational or practical nursing programs were evolving. Dorothea Orem was beginning her work on formalizing nursing while studying hospital nursing services in Indiana. Her work and the work of other theorists had not yet influenced nursing. Most nursing positions, jobs, were within hospitals. Practice areas were referred to as medical, surgical, psychiatric, pediatrics, and obstetric nursing, using the nomenclature of the usual medical specialties. Nurses were assigned to a unit or ward with a strong Head Nurse who ran the unit and was liaison between the patient and family, physician and staff. The work of caring for patients was structured along functional lines - one nurse did meds, another treatments, another did the hygiene care for complex patients, assisted by nurses' aides and orderlies (by gender). There were no recovery rooms or intensive care units. Patients were recovered by nurses on the unit. In more complex situations, a special, private duty nurse was employed to take care of a single patient, paid directly by the patient or family for the service. Using a sphygmomanometer was considered high tech for nurses. We prepared our own injectables, rewashed, sterilized and reused syringes and equipment.

Public health nursing and community nursing were recognized as separate and distinct, with specific important roles. In those days, the public health nurse (PHN) did health screenings in the schools, immunization and well-baby clinics and contagious disease surveillance which included posting quarantine signs for communicable diseases such as measles, mumps, chicken pox, TB. In my city, the PHN delivered the birth certificate and a copy of Dr. Spock's baby book (Spock, 1957) to each new mother as a way to do follow-up and assess the home situations. Mothers were taught how to bathe and feed babies and appointments were made for well-baby checks.

Community nursing focused on home care such as was provided by the Visiting Nurse Association. There were county or city homes for the aged poor but few nursing or assisted living facilities as we know them today. It was the norm for the family to take care of the aging and ill members with the assistance of a Visiting Nurse.

I could go on and I'm happy to share stories but there's limited value for our purpose in reminiscing other than to understand that "what is past is prologue." What was happening then influenced what is happening now. I'll leave it to our nurse historians to continue to help us understand how we have progressed as a profession.

Over time, the dynamic energy that is nursing recognized the limitations in these approaches and saw the potential for improvement. Change became a recognized way of life within the profession, to the extent that we thought it worthwhile to teach nurses to be "change agents". These changes were accompanied by varieties of social political issues that are still being dealt with such as licensure, independent practice and prescribing rights.

3 PRESENT

What is nursing like now? Those who are currently active can probably describe it better than I. Nursing education programs are burgeoning throughout the world. There are multiple forms of graduate nursing education with a variety of research and practice focuses. The baccalaureate is becoming the standard for general nursing.

As for practice, there have been so many changes. To name just a few - greater diversity of roles, and diversity of practitioners; increasing job opportunities within and beyond the hospital (so many that I don't know how one chooses), increasing technology to support nursing in the provision of care to persons, families and communities.

Since I retired in 2000, my knowledge of contemporary nursing has been formed by and reinforced through family experiences, continued reading and study, and discussion and reflection with other nurses and health care providers (that term alone reflects some major changes.)

My knowledge of contemporary acute care nursing was recently enhanced or sharpened when I was admitted on an emergency basis for a laparoscopic cholecystectomy. After a very unpleasant evening suffering an acute episode of vomiting and pain, a friend took me to the emergency room at the community hospital. It was a quiet Friday night in the ER, so I was immediately tended to. The staff was friendly and competent. Thanks to technology all the information they needed was in the computer, just needed to update medications being taken. (Not at all like the comedic scene of the person slowly bleeding out while having to complete pages and pages of insurance and health data before being seen by a practitioner.) A CAT scan showed gall stones blocking the gall bladder. The surgeon was called and the decision for surgery was made. I would stay in the hospital overnight and have the procedure on Sunday. I was moved from ER to a new high tech patient surgical tower with private rooms.

Activities generally accepted to be within the broad field of nursing were performed by minimally trained patient care technicians (PCT), e.g., monitoring vital signs, checking dressings, answering call bells under the direction of the registered nurse. It was an interesting experience. I felt confident that I was being well taken care of by friendly, competent, caring people with defined roles. However, the constant stimulation of the environment drove me to the edge. The bed was moving - alternate zones inflating and deflating. (I wouldn't get skin breakdown nor would I get a good night's sleep.) Pillows were encased in plastic, hygienic but uncomfortable. Each piece of electronic equipment had its own individual harmonic and beep, the air climate control was blowing, lights were always on. Being new, there were many unpleasant odors in the environment. To a great extent, the amount and quality of care depended on my ability to describe and interpret my sensations and responses (is this self-care?) having to rate my pain on a scale of 1-10 was a daunting task for me. Needless to say, I was much too analytical about it, only to find that it didn't mean a whole lot. The nurses used their own observational skills and knowledge base to assess the need for analgesia. But by documenting my numeric responses, they were able to demonstrate that they were assessing and managing my pain. What's that saying - "if it isn't written down, you didn't do it"?

And so on the second post-op day I was discharged to home. There was some talk of discharging me on the day of surgery or the following day. Consultation amongst myself, the nursing staff, and others kept me in the hospital until the morning of the second day post op. There was substantive discharge teaching and queries regarding my ability to care for myself or the existence of support systems.

So now, a procedure that 50 years ago or less would have involved a major incision, drains, dressing changes, long hospitalization, and probably a higher incidence of complications would also have involved more personal care by nursing staff, giving the nurse a greater opportunity to know the patient as person with family, to have a broad focus on health and well-being and on integrating events into life system. "Participation is at the foundation of personal existence…and entails joining with others in shared activities, purposes, and goals and consists in engagement with others…" (Taylor & Renpenning, 2011, pp. 105-106). Nurses are challenged to maintain this personalism in the contemporary acute care environment and time-limited interactions. However, nurses are moving into new arenas of practice that incorporate personalism as an essential aspect of practice.

And while we lacked a way to talk about what we did and thought as nurses, we knew how to do nursing. We took care of the body with comfort and hygiene measures, hopefully conveying to patient and family humanness and empathy in the relationships, treating the patient as a person with inherent value in our interactions. At least that was a value and goal. Did we always meet it? Of course not. But when we didn't, as now, when we treat the patient as object, we diminish ourselves, the patient and the profession.

4 FROM PAST TO PRESENT

In the time leading to the present, dramatic shifts occurred in the appearance of nursing, nursing education and health care. The locale where care is delivered has changed, new and additional activities have become expected elements of the nursing role. The incorporation of technology in all aspects of work and life continues to challenge personal and professional roles and activities.

More of the acute care can be managed by well-educated and trained technicians and technologists. This could leave professionally educated nurses for delivery of complex patient care, leadership, development, infusion of innovation, design, research and educational roles associated with differing levels of education.

In the developed nations, we have a greater understanding of the elements of health, and its relationship to well-being, the importance of taking care of ourselves and others, and the need to incorporate all of this into a satisfactory way of living. From our early history, nurses knew that promotion of health and prevention of illness went side by side with care of the ill, infirm and injured. We know now, in ways we didn't 50 years ago, the importance of developing an integrated self-care system from birth to death. And the importance of developing social systems that enable persons to do this, including education, development of information systems to access quality information, and home and community-focused programming. Today the U.S. is struggling with establishing systems that enable all persons to access quality health care. There is a need to help persons develop reasonable expectations as to what can be done; recognizing that just because something can be done doesn't necessarily mean it should be done. We see this in the development of palliative care initiatives and hospice programs, for example. As a society, perhaps we need to dial back our expectations and clarify our basic values. There are some serious ethical questions embedded in these ideas.

In 1960, I returned to the University to do graduate work in nursing. From my perspective, the greatest change leading up to the present is in the ways in which nurses are educated. From a rather singular model of hospital-based in-service training, with few baccalaureate and graduate education programs, there now is a complex multi-level plethora of education and training programs. During the 1960-70's, Dorothea Orem and other scholars were developing definitions and models of nursing to bring structure and clarity to the practice and knowledge base of nursing as a discipline. In my BSN program we worked from a Christian, scholastic perspective of the human person as having needs and value, existing within a family and community that had shared responsibilities for care/caring. We learned a definition of nursing written by Sr. Olivia Gowan (Renpenning & Taylor, 2003, p. 155). We wrote nursing case studies that incorporated these needs and resources. We came to understand the patient as person and their medical and health needs. From this we were asked to draw "implications for nursing". What did it mean for nurses if a person received a particular medicine or form of treatment? If a broken leg was put into a plaster cast, what did we as nurses need to observe for or do to maintain comfort and safety? All of our knowledge was viewed as derivative. Through the centuries, we had developed a body of knowledge on how to do things in particular circumstances. In my masters program, for example, I learned how to write procedures using principles of anatomy and physiology, considering logical sequencing of actions including materials needed, time, expected outcome and so forth intuited from disparate bodies of knowledge. At that time the idea of nursing care plans was emerging. We were directed to take doctors' orders and translate them into sets of actions to be performed at particular times with some expected outcome related to the medical diagnosis. Also, about this time nursing scholars began to see a need for some organizing structures for nursing knowledge. One of the first proposed was that of basic human needs as identified by other disciplines.

In 1968 I returned to the University for a doctoral degree and reached the stage of doing a research project for my dissertation. I'd had a difficult time finding a question for my master's thesis and was not looking forward to the prospect of identifying one for my doctoral research. I was assigned a director/advisor who took me in hand and asked the simple question "where or what is your conceptual framework?" It took me a while to understand the question but with that insight my life changed.

And so did my approach to nursing knowledge. For at the same time as I personally was gaining these insights, nursing educators and scholars were working on the same issue - what is the structure of the disciple of nursing, what is the essence of nursing, what is nursing science? A number of related but separate answers were proposed. Any one familiar with the history of nursing knowledge development knows what these are.

My intellectual development led me to explore work that was being published. A friend sent me a copy of Orem's Nursing: Concepts of Practice (1971), and for me the die was cast. From that time on I was able to see nursing as a science and discipline with a proper object. Nursing became something to know not just something to do. I was fortunate to be able to work with Dorothea Orem and her colleagues from the mid-1970s on. I accompanied her to nursing theory conferences in the U.S. and Canada. And I was privileged to work on theory development and utilization with her and many other nurses. And here we are today, at a major international conference focusing on the science of self-care manifest as active aging.

5 THE FUTURE

So, all that said, what does the future look like for nursing within health care? While we cannot know for certain, it is possible to identify some trends and significant issues.

Trends in Practice

There will be increasing expansion of roles and responsibilities and continuing split and specialization within nursing. One focus will be on primary care for many and various age groups, including chronic disease management. Another will be high-tech acute episodic care in more and more sophisticated facilities using many different technologies of therapy each requiring a specialist to manage the care for the person, e.g., nurse intensivists, transplant nurses, trauma nurses. The use of paranursing technicians will need to be carefully managed by professional nurses. Most of the care will require nurses with BSN degrees or higher. The Institute of Medicine (2011) recommendation is that 80% of nursing staff in acute care hospitals be baccalaureate educated.

The emerging focus on patient-centered care will require greater nurse and physician collaboration changing from that of physician dominanted to shared practice and decision making; independent professionals in true collaboration. The current movement is to engage each person in a medical home (National Conference of State Legislators, 2011, Veterans Administration). According to the principles, patient-centered medical homes should have these characteristics: a personal physician, physician-directed medical practice, whole-person orientation, coordinated care, quality and safety, enhanced access and adequate payment. In this new model, the traditional doctor's office is transformed into the central point for Americans to organize and coordinate their health care, based on their needs and priorities. At its core is an ongoing partnership between each person and a specially prepared primary care physician. This new model provides modern conveniences, like e-mail communication and same-day appointments; quality ratings and pricing information; and secure online tools to help consumers manage their health information, review the latest medical findings and make informed decisions. Consumers receive reminders about necessary appointments and screenings, as well as other support to help them and their families manage chronic conditions such as diabetes or heart disease. The primary care physician helps each person assemble a team when he or she needs specialists and other health care providers such as nutritionists and physical trainers. The consumer decides who is on the team, and the primary care physician makes sure they are working together to meet all of the patient's needs in an integrated, whole person fashion. While the concept is being put forth in medical terms because our health care system is so medico-centric, it could be done by nurse practitioners. Furthermore, it is an expensive resource intensive system that will not provide services to the poorest of the poor. One of the problems is that consumers are not knowledgeable about how to use the system nor is health the priority in their lives. This will be required to make such a system successful. This will require more of a paradigm shift on the part of physicians. Nursing has the advantage with its history of patient/person centered care, and team nursing.

Given the capability for electronic health record keeping, we need to capture nursing data in ways that keep the nursing meaning so that we do not lose all the potential nursing knowledge that can be developed through the use of large data sets. This is particularly important in chronic disease management where self-care science is more nursing focused. The SCDNT can provide the structure for the data gathering and interpretation.

With the shorter hospital stays, the arena of home care, i.e., care provided to ill, infirm, fragile, vulnerable persons outside of institutional settings, will increase or other kinds of care facility will develop. With an emphasis on "aging in place" there is an increasing demand for persons to provide in-home care and management of the home. While this can be done by minimally trained workers with home-making skills, there is a need for surveillance and development of self-management systems. If this is not attended to, the rate of re-admission will continue to be high as will the cost of care.

The continuing development of professional nursing is also an important part of the future. How the nurse is socialized to become the expert professional will be better understood, leading to development of internships and mentoring opportunities within the field. Luntley (2011) suggests that the professional knowing nurse is not the nurse who knows all the answers, but is the nurse with the attentional skills to keep pace with what she/he and colleagues are doing, how they are doing it and to be able to pick it up in thought and make it something for which there are reasons for doing. This is the nurse who knows how to go on. The professional nurse must retain the responsibility for designing systems to use the technologies for cohorts of patients.

Trends in Education

From my perspective, the greatest change has been and will continue to be in the way in which nurses are educated. Nursing went from a rather singular model of hospital-based training programs, and a few baccalaureate programs, to the current complex multi-level plethora of programs. Whether this is a good thing is yet to be determined. Parse (2012) recently commented on this raising many questions regarding the real differences in these programs, both content and outcomes and whether these make a difference in healthcare delivery. Ultimately the question of concern is the development of nursing science and knowledge. There will be a strong focus in the curriculum on biosciences such as anatomy, physiology, pharmacology, genetics, etc. The concern will be on the life processes, maintaining and extending life. This content will need to be balanced with the human personal sciences or fields of knowledge and development of critical thinking skills. There is a need to recognize that a professional masters or doctoral degree will be the minimum preparation for a professional nurse to meet role expectations. I believe that the SCDNT provides structure for examining the question of how one conceptualizes nursing in high tech practice. Nursing education may be reaching a point where basic programs should structure their curriculum on the nursing sciences of wholly compensatory, partly compensatory and supportive-developmental nursing systems.

More of the education will be conducted through electronic media. Programs can be interdisciplinary and global, not limited to a particular site. The challenge is to maintain the quality of the practice component, including interpersonal skills and socialization to the profession.

Changes in education lead to issues regarding the organization of the profession and workforce. There must be a synergy between practice roles and education. We must continue to develop technical and /technological education programs that will provide the high levels of skill needed to care for patients in high tech environments. These may well be at the baccalaureate level of education. We need to develop technologies related to self-care of persons in different settings and develop/educate technicians to implement those technologies. Programs need to include policy issue development and engagement opportunities within health care institutions and the broader society.

Nursing education should be structured with a conceptual framework that is nursing specific. We have gone beyond the point where nursing knowledge is derivative to that of having our own evolving science. The changing role of nursing within the health care system (from the doing to the thinking) will impact educational programs so as to facilitate the development of nursing science. How is the nurse taught to keep the focus on the person in the midst of all the technology? While it is imperative that the technology be used and managed to get the best outcome for the patient, it is also imperative that we treat the patient as subject, not merely as an object (Taylor & Renpenning, 2011).

Trends in Knowledge Development

Moving forward in development of the SCDNT needs to be collaborative between practice and education. In addition to enhancing the science of self-care (which is often interdisciplinary), the development of the nursing sciences and applied nursing sciences must continue. Doctoral programs, both research (PhD, DNS) and clinical (DNP) need to have knowledge development as a major outcome of the educational endeavor. And the rigor of the research must be upheld. In the US, the National Institute of Nursing Research (NINR) has identified areas of research the results of which will help move us into the next decades. (NINR, 2011) They are: to enhance health promotion and disease prevention, improve quality of life by managing symptoms of acute and chronic illness,

improve palliative and end-of-life care, enhance innovation in science and practice, and

develop the next generation of nurse scientists. which will help move us into the next decades. (NINR, 2011) They are: to enhance health promotion and disease prevention, improve quality of life by managing symptoms of acute and chronic illness,

improve palliative and end-of-life care, enhance innovation in science and practice, and

develop the next generation of nurse scientists. NINR now focuses its mission on the science of health, which focuses on the promotion of health and quality of life. The science of health is based on the premise that individuals would benefit from being actively involved in maintaining their own health through the prevention of disease and the direct participation in the management of illness. In the U.S., self-care is still thought of as patients doing their own medical treatments, a very limited conceptualization.

Another issue is how disciplinary knowledge development will emerge in an era of interdisciplinary collaboration? Parse (2012) says "Collaboration by nurse researchers with interdisciplinary colleagues is useful only if it is true collaboration, where the voice of nursing is clearly evident in the conceptualization of the research studies and where the findings enhance understanding of the phenomena embedded in the theoretical basis of nursing" (p. 125).

6 CONCLUSION

There are some things that have not changed, that are enduring. These include the importance of nursing to patients and families, and the trust they place in nurses, the cooperative nature of health care within the complex of person/family, community and health care providers, i.e. nurses, physicians and others, in developing and providing service - and most importantly, understanding of what is the essence of nursing and the contributions nursing can make to society. While there have been changes in the accidents of nursing, i.e. the describing characteristics, the essence or substance of nursing has not changed and should not be allowed to change. But it does need to be formalized and made known.

The future will continue to bring greater technological change that will need to be incorporated into a care system that has as its goal the health and well-being of individuals. Continued development of the integrated science of self-care and action programs to improve self-care capabilities could do much to improve the human condition. The use of a conceptual framework reflecting the concerns of nursing, through nursing theory and nursing science, must take precedence over theory derived from conceptual frameworks associated with related disciplines. While there is a push for interdisciplinary collaboration, we can only be collaborative when we bring our unique disciplinary perspective to the endeavor.

These projections are logical considering where we've been, how we've gotten to where we are. The difficulty is that they are mostly idealized without consideration of context. We are in the midst of difficult economic times. In the U.S. there is much disagreement about the direction health care should take; much will depend on the outcome of our elections in November. Though we are in a time of accelerating change, it might be nice if we could slow down, let us live with what we have for a while, let our human systems catch up, let us see what some of the effects of these changes are on our health and well-being. Let us see what is important to our existence as persons.

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SELF-CARE IN THE CONTEXT OF NURSING AND THE HEALTHCARE SYSTEM IN THAILAND

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KEYWORDS

community based care, chronic illness, primary care, self-care, self-management

1 INTRODUCTION

At present, the world is facing many challenging health problems. One is the rapid rising of chronic illness and aging population along with the advancement of medicine and technology, resulting in high cost of care. This leads to inequity in access to healthcare services, especially for the poor and disadvantaged groups. In addition, social conflict, unrest and natural disaster destabilize service resources. Global warming and immigration of people around the globe results in emergence of new diseases as well as endemic and pandemic ones. At the same time, fiscal resources are limited by nurses and health workers shortage and mal distribution, while there is increasing consumer expectation and demand. Thus, healthcare systems in many countries are facing serious challenges and need to be reformed to meet the need for access to appropriate, affordable care of its people. Therefore, making the shift to primary healthcare and community based care is inevitable.

In 1978, World Health Organization (WHO) declared the goal of health for all by the year 2000 and identified primary healthcare (PHC) as the means to achieve the goal (WHO, 2008). Health for all is defined as "stage of health development, whereby everyone has access to quality health-care or practices self-care protected by financial security so that no individual or family experiences catastrophic expenditure that may bring about impoverishment" (WHO, 2008, 12). Strengthening primary healthcare is necessary to ensure universal healthcare coverage with reasonable cost and acceptable quality and is the basis to improve healthcare service at all levels. International evidence suggests that health systems based on strong PHC orientation have better and more equitable health outcomes, are more efficient, have lower healthcare costs, and can achieve higher user satisfaction than those whose healthcare systems have weak PHC orientation (Pan American Health Organization, 2007). Thus, PHC is now more than ever needed to make sure the unreached can be reached, the poor can be served, communicable diseases can be eliminated, chronic illness can be prevented and managed, and communities have access to health services (WHO, 2008).

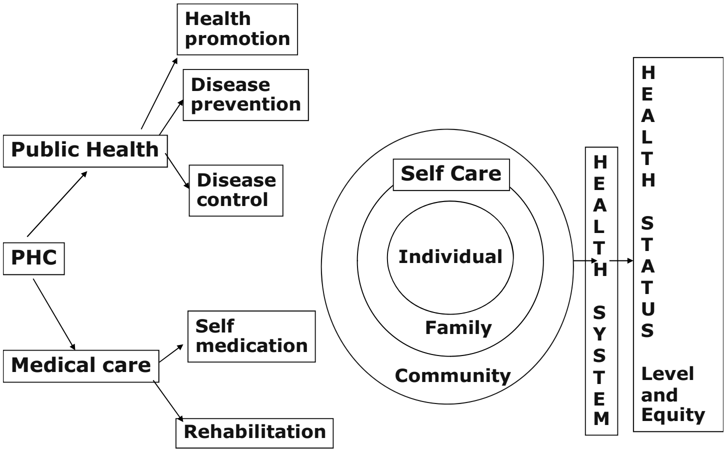
In January, 2009, the WHO office of the South East Asia Region Office (SEARO) provided regional consultation on "Self-care in the Context of Primary Healthcare" in Bangkok, Thailand. WHO/SEARO envisioned that, in order to achieve national and international health goals, sustained self-care promotion should be an essential component of revitalization of primary healthcare. Many believe that effective self-care is important not only to reduce healthcare costs but also as an instrument to produce health equity. Thus, WHO/SEARO requested the member states to respond to the following: a) give serious consideration to strengthening self-care as a program in their efforts to revitalize primary healthcare; b) re-examine national health policies and strategies to strengthen support structures, legislation and financing for self-care; c) document existing local self-care best-practices and conduct operational research to develop evidence-based effective self-care practices; and d) establish a network of individuals and institutions for self-care promotion.

2 SELF-CARE IN THE CONTEXT OF PRIMARY HEALTHCARE

In the context of primary healthcare, self-care permeates all types of care both in public health and medical care (see Figure 1). Public health includes health promotion, disease prevention, disease control and early detection. Medical care is comprised of self-medication and rehabilitation. Self-care is performed at various population levels from individual, family and community. The benefit of self-care includes: reduction of the burden of overstretched health system, reduced cost, increased effectiveness and facilitating the effort to achieve universal coverage. At the individual level, self-care has a positive impact on the economy. On a large scale, it can substantially contribute to alleviation of poverty, especially in poor communities. And, self-care, correctly practiced, can contribute immensely to rational use of medicines (WHO, 2009).

Ferguson (1992) pointed out that, in the era of industrialized medicine, even though self-care was viewed as the basic resource for healthcare, it was not a part of the healthcare system. This conceptualization limited the participation of individuals, families and communities in taking an active role in the healthcare system. However, in the era of information age healthcare, individual self-care, family and volunteer care, and professional and institutional care are accepted.

Figure 1. Self-care in the context of primary health care



SEARO WHO 2009 p. 25

3 CONCEPTUALIZATION OF SELF-CARE AND SELF-MANAGEMENT

The complexity of health problems and healthcare needs of the people requires expertise from each healthcare provider to work collaboratively as a team to achieve better outcomes. Effective communication is vital. Nursing theory is viewed as important for knowledge development in the nursing discipline. In order for nursing to assume its place in the healthcare system, nursing theoretical guidance must be shared with other disciplines. Nursing leaders must communicate what nursing is doing and why. (Taylor and Renpenning, 2012). The concepts of self-care and self-management have been fully explicated and are taking their place in the healthcare scene.

4 SELF-CARE

The concept of self-care is prominent in policy documents in many countries WHO (2009). Various disciplines agree that self-care must be integrated in all levels of the healthcare system. This requires healthcare providers to understand and share conceptualizations so that collaborative effort can be maximized.

Orem defined self-care as deliberate and purposeful action to maintain life, health and promote development (2001). Self-care involves reflection, judgment, and decision making prior to taking actions and is learned in the cultural context. Self-care behavior is the result of the operations of deliberate action of knowing (estimative), decision making (transitive) and acting (productive). This definition provides the framework to promote self-care agency to meet self-care demands in specific health problems of individuals, family and community. The unique responsibility of nursing is to design nursing systems to maintain balance between therapeutic self-care demand and self-care agency/dependent care agency. The roles of the nurses are: 1) performing self-care demand for patients when patients are unable to do it, 2) working together with the patients to meet their self-care demand and 3) supporting, coaching and educating patients to perform their self-care demands in the face of illness or injury (Orem, 2001).

WHO's working definition of self-care is close to Orem's (2001) in that self-care is defined as a deliberate action and the ability of individuals, families and communities to promote health, prevent disease, and maintain health and to cope with illness and disability with or without the support of a health-care provider (WHO, 2009). The Department of Health in London (2005) cited in Rijken *et al.*, 2008, 117) uses a similar but slightly elaborated definition of self-care as "the actions people take for themselves, their children and their families to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long-term conditions; and maintain health and well-being after an acute illness or discharge from hospital". Self-care is essential for everyone in any state of health - from healthy, at risk of ill health, experiencing symptoms, being diagnosed with an illness or receiving treatment. Specific self-care in illness includes: self-diagnosis, self-management, self-medication and self-monitoring.

In conclusion, even though self-care may be defined differently by various disciplines, the definitions share many similar characteristics and a common goal. Among the similar characteristics are:

- self-care skills and knowledge stem from lay experience.
- self-care is a part of daily living.
- self-care involves a partnership between individuals, families, caregivers and healthcare profession.
- healthcare professionals may or may not be involved.
- self-care is work required by everyone (Orem, 2001).

5 SELF-MANAGEMENT

Self-management is usually used in policy, practice and research in chronic illness. According to Orem (2001) self-care requires self-management. Self-management denotes the active participation of patients in their treatment. The aims of self-management are to 1) minimize the impact of chronic disease on health status and functioning, 2) enable people to cope with the psychological effects of the illness, 3) prepare patients to engage in medical management, 4) maintain life roles, 5) manage negative emotions such as fear and depression and 6) acquire the necessary knowledge, skills and confidence (self-efficacy) to deal with disease-related problems (Rijken *et al.*, 2008).

Self-management support involves a patient-centered collaborative approach to empower and prepare activated and informed patients to manage their health. Self-management support expands the role of healthcare professionals from delivering information and traditional patient education to helping patients build confidence and make choices that lead to improved self-management and better outcomes (Coleman and Newton 2005 cited in Rijken *et al.*, 2008). Persons with chronic illness need to change some behaviors to meet self-care requirements to control disease as well as minimize its impact on their lives. Various theories are used for self-management support: social cognitive learning theory, rational theory, stress coping theory; theory of reason action and change theory (Rijken *et al.*, 2008). Self-management programs usually include: patient educational sessions, cognitive restructuring, problem solving, skill training, goal setting, and the use of evidence-based standardized interventions in chronic conditions such as diabetes, patient motivational counseling and distribution of educational materials. A review of studies revealed that 19 of 20 studies which included a self-management component improved outcomes (Bordenheimer *et al.*, 2002).

6 PROMOTION OF SELF-CARE IN THE CONTEXT OF NURSING AND HEALTHCARE SYSTEM

Government policy direction and commitment are a prerequisite for promotion of self-care with professional support. Promotion of self-care is best pursued within social and cultural contexts and requires an educational and empowering process that ensures that people receive the right information to make decisions regarding their own health. Health education includes consciously constructed opportunities for learning involving some form of communication designed to improve health literacy (WHO, 2009). In this era of information age, there is endless information available. However, not all is the right information for effective self-care. It is the duty of health professionals to help people to choose the right information in specific situations. Advancement in information and communication technology (ICT), if properly used, will greatly contribute to efficiency and effectiveness of self-care promotion.

Although the healthcare system must be designed to incorporate self-care at all levels, the most appropriate level is the community. Thus, healthcare policy in most of the country emphasizes community based healthcare to improve accessibility to quality of care for all. Nurses are the key healthcare providers in the community. Nursing's unique concern is "the inability of persons to provide continuously for themselves the amount and quality of required self-care because of situations of personal health" (Orem, 2001, 20). Nurses not only promote self-care but also provide the care in cases where patients' self-care demand is complex and family members, friends and networks may not be able to meet their self-care demands.

7 PROMOTION OF SELF-CARE THROUGH COMMUNITY BASED HEALTHCARE FOR CHRONIC ILLNESS: THAILAND CONTEXT

Community-based healthcare is care that is taken place in the community and home settings and involves individuals, families and community members in the design and implementation of services. Community-based healthcare plays an increasingly important role in many countries, including Thailand. Under the philosophy of economic and health sufficiency as well as the human caring society, Thailand National Healthcare Plan envisions that community-based healthcare can be expected to meet the goals of community health systems. The scope of community health based care includes;

1. Case finding and helping the vulnerable, disadvantaged, disabled and neglected people in the community.
2. Treating common and acute episodic illness.
3. Supporting self-care and self-reliance.
4. Managing persons with chronic illness/conditions.
5. Caring for dependent elderly persons with chronic illness/conditions at home.
6. Surveillance control of chronic and endemic disease.
7. Integrating reliable complementary therapy/Thai traditional medicine.
8. Promoting community health.
9. Building healthy community environments.

Thus community based health can be expected to lower the costs of care, improve quality of service, improve access to more appropriate services and reduce the inequities in the population's health. Other benefits include integrated, accessible healthcare services by primary care providers who are accountable for addressing a majority of personal healthcare needs, sustained partnership with patients and care provided in the context of the family and community.

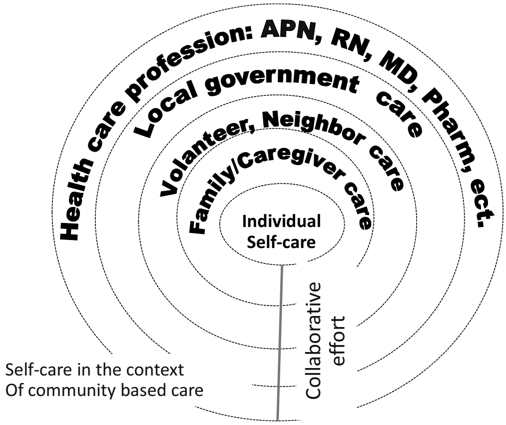
The incidence of chronic disease has become rampant (WHO, 2008). An integrated approach is needed for prevention, control, rehabilitation and health promotion. All chronic diseases place comparable demands on healthcare systems. At the same time, medical care for chronic illness is rarely effective in the absence of adequate self-care. Self-care and medical care are both enhanced by effective collaboration among chronically ill patients, their families, healthcare providers and community members. Given the long-term nature of these conditions, governments and health service providers are engaged in initiatives to develop new ways of supporting people living with chronic conditions to manage their own health. Support for people to self-care is, therefore, a vital element of any policy to tackle the rising tide of chronic disease (Nolte and McKee, 2008). The Wagner Chronic Care Model (Wagner *et al.*, 2001) has been implemented in many countries, including Thailand. Self-management support is a key feature of the Chronic Care Model (CCM), which emphasizes the centrality of an informed, activated patient and productive patient-provider interactions.

There is substantial evidence from over four hundred studies of self-care and self-management that programs provided counseling, education, information feedback, training skills, and other support are associated with improved outcomes (Center for Disease Control, 1996 cited in WHO, 2002). Also, including patients in decision making and treatment planning makes delivery of care for chronic illness conditions more effective and more efficient (Holman and Lorig, 2000, cited in WHO, 2002). A success story of self-care/ self-management in the family and community will be presented here. The example is the care service provided to two groups of patients and families with 2 kinds of chronic illness: chronic obstructive pulmonary disease (COPD) and hemophilia at a community hospital in Thailand.

In Thailand, COPD is ranked as the fifth leading cause of death with a mortality rate of 33.5, and the second most common cause of disability-adjusted life year (DALY) worldwide (HSRI, 2007). By the year 2010, the prevalence rate will increase from 2075 to 7035.3 per 100,000 of the population (Chuprapawan, 2007). Patients with COPD are high in dependency due to their functional decline related to old age, cognitive impairment, living alone, feeling of helplessness, resulting in inability to adhere to medication regimen and pulmonary rehabilitation. More than 10% of the patients in this community hospital are readmitted to the hospital 1-2 times/month with a length of stay more than ten days, some more than 2 months . The quality of life index of the patients is low to moderate level. (Suriyathai, 2010).

The advanced practice nurse (APN) who is responsible for prevention and management of chronic illness in this community hospital led the team in implementation of home and community-based care for all chronic illnesses, including COPD. Wagner's CCM (2001) was used as the framework. Care teams are comprised of patients, families, relatives and neighbors, community health workers, health volunteers, local government workers and healthcare professions. The services include prevention through end of life care. Each team member has unique responsibilities and works collaboratively to ensure the continuity of care and good outcomes for patients. The goals of healthcare services are to build the capacity of patients, families and all community resources for self-care and self-reliance. Healthcare providers are at the outermost circle of self-care. Their role is to facilitate all stakeholders including patients to effectively manage the care demands of the patients. The model is shown in Figure 2. The patient is responsible to perform self-care, carry out the daily duties when the condition allows. Family help the patient identify and meet care needs. Neighbors assist in delivery of medications and equipment such as oxygen tanks to patient's homes. Care teams from the health district or health promoting hospital include health volunteers, community health workers and nurses. The teams provide home care according to clinical practice guidelines for monitoring health conditions and ensure adherence to medication and pulmonary rehabilitation. They also provide care for acute episodes such as exacerbation of dyspnea. Local government workers participate in creating healthy environments and transferring patients to the hospital when acute dyspnea cannot be controlled. The APN leads the team by providing case management and direct care to patients with complicated problems. Also the APN establishes the system to assure continuity of care by collaboratively working with care providers in every primary care unit and networking with the community hospital. Physicians are responsible to reassure the patients at home, act as a consultant to the APN and other healthcare providers and to as assist the APN with approved modified clinical practice guidelines.

Figure 2. Self-care in the context of community based care



A three year evaluation of APN managed home and community based care revealed:

- decreased numbers of patients with acute exacerbation each year.
- decreased severity of illness.
- decreased readmission rate.
- shortened length of hospital stay.
- reduced cost of care.
- increased QOL index of patients (Suriyathai, 2010).

In addition, the patients participate in family discussions and decision making. Patients are not exposed to the hassles of a fixed routine at a hospital and the increased risk incurred during hospitalization. Family members are empowered to offer care to the patients, have no expenses for traveling to visit the patients and family unity is maintained despite the sickness. Community members are empowered with knowledge and skill on prevention, care treatment and support and enhanced unity. Finally, the health system is less stressed, therefore being able to offer overall care to all in need.

In the case of children with hemophilia, the children and their parents were faced with difficulty living with the disease, negative attitudes toward the disease and toward self since they lacked knowledge related to self-care requirements and were unable to manage care for themselves. Many of these children were living on a mountain far away from the hospital so they could not access the healthcare system. They experienced uncertainty and insecurity in their lives. They felt powerless and helpless because of their inability to predict and control bleeding when it occurred.

The same APN, who is the leader of the care team, works collaboratively with all healthcare providers in the community and with hemophiliac children and their parents with the aim to:

1. Increase knowledge and understanding of the disease, treatment and self-care management.
2. Teach effective self-care management.
3. Decrease complications.
4. Decrease healthcare utilization.
5. Increase quality of life.

Clinical practice guidelines from World Federation of Hemophilia (2005) were implemented. This guideline focuses on 4 essential self-care requirements:

1. Prevention of bleeding.
2. Treatment of early bleeding with home based care .
3. Long term care for joints and muscles.
4. Management of complications from treatment

The APN plays an important role in providing self-management support to hemophiliac patients and their parents. The APN and a proactive care team and informed, activated patients and families act together to meet all self-care requirements at home or the closest primary care unit. The children are taught to self monitor for bleeding and to self inject the coagulation factor to stop bleeding with the support of parents or relatives who live nearby in the community. The APN also works with the National Health Security Office to bring all patients in the province and surrounding areas under the universal coverage scheme payment of the country. Also, she facilitates the organization of friendship therapy and self help support groups among parents of children with hemophilia.

The three year evaluation showed:

1. All patients were registered in NHS program and could access healthcare.
2. Knowledge of hemophilia and self-care requirements increased.
3. Ability to perform activities of daily living increased.
4. Ability to attend school and work increased.
5. Cost decreased 44.48% (from 20,600 USD/year to 11,450 USD/year).
6. Hospitalization decreased.
7. Patients and family satisfaction was 95.50%.
8. There was no increase in joint deformity.
9. The mean average of sickness related to hemophilia was 1.25time/month.
10. There were no reports of complications from treatment or from having antibodies to blood coagulation.
11. QOL was increased to middle level.

In conclusion, a community and home based healthcare system is essential for effective care of persons with chronic illnesses. The key to success is promotion of self-management by patients and families, supported by healthcare providers and all resources of the community. The APN can lead and build the capacity of the team to meet the demands of persons with chronic illness.

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Awarded Speakers

RESIDENTIAL CARE FOR OLDER PERSONS IN BELGIUM: WHAT ARE THE FUTURE NEEDS?

PROJECTIONS OF RESIDENTIAL CARE USERS 2010 - 2025

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ABSTRACT

Demographic ageing of the population in the coming decades is expected to have significant implications for the needs for and use of long-term care (LTC). The objective of the study reported here was to develop a projection model of the number of users of residential care, taking into account variables related to population structure in terms of sex and age, living situation and the availability of informal carers, and trends in disability. The construction of the projection model proceeded in three steps. First, logistic equations incorporating the most important variables determining residential long-term care use were estimated, using data from a large administrative panel for the Belgian population aged 65 and over. Secondly, from these equations we derived quarterly transition probabilities between ten LTC situations, conditional on sex, age, living situation, disability and province. We distinguished the following care situations: no care, home care (two levels), residential care (five levels), hospitalization and death. In the third step, these transition probabilities were used in conjunction with populations forecasts to produce projections of the number of users of residential care in Belgium up to 2025. We present results for a base (demographic) scenario and for five alternative scenarios, based on different hypotheses about future evolutions in disability, household situation and the availability of informal care, and the future use of formal home care. According to the base scenario, the number of older persons in residential care is projected to rise from 125,500 in 2010 to 166,000 in 2025, which is an increase of 32%. The projected rise is smaller if the age-specific incidence of some chronic conditions would decline, or if home care could be expanded considerably beyond the increase that is already required by the ageing of the population.

KEYWORDS

long-term care, population ageing, projection model, residential care

1 INTRODUCTION

It is well known that due to the ageing of the population the demand for long-term care (LTC) will expand strongly during the coming decades, especially since the largest increases are expected among the oldest old, who are the most important users of LTC (cf. Colombo *et al.*, 2011). In its 2009 Ageing Report, the European Commission (2009, 131-146) projects that public expenditure on LTC will nearly double in the European Union between 2007 and 2060, rising from 1.2% of GDP to 2.4% (following the prudent 'AWG reference scenario'). For Belgium an increase from 1.5% to 2.9% is projected. Residential care is the dominant component of LTC; statistics from the Organization for Economic Cooperation and Development (OECD) indicate that in Belgium in the year 2009 11.9% of total public health expenditure was spent on LTC in nursing and residential care facilities, while home LTC accounted for only 5.4%. 2)

The federal structure of the Belgian state has resulted in a complex system of LTC, where governments at several levels have various responsibilities (Willemé *et al.*, 2011). As regards residential LTC, and somewhat simplifying, public funding comes mainly from the federal health insurance system, while the regional authorities regulate the provision of LTC services. The latter are also responsible for approving new facilities and the expansion of existing ones. In order to keep the system governable, the regional and federal authorities concerned have over time made a number of protocol agreements. The last one of 2005 included a moratorium on the number of beds in residential care, while also aiming to support older persons living at home, and an improved financing system for residential care. This agreement was due to expire at the end of 2011 (though it has been extended now).

In order to be able to make informed choices about residential care in the next protocol agreement, and in view of the imminent strong increase in the number of older persons as the baby-boom cohorts are now starting to enter retirement, the Federal Public Service for Health wanted to obtain an estimate of the future number of users of residential care. The study was carried out by the Belgian Federal Planning Bureau, in cooperation with the Belgian Health Care Knowledge Center (KCE). The terms of reference of the study were rather specific : only a projection of the number of users of residential care between 2010 and 2025 was required. Home LTC was not included (except possibly as a side constraint), and costs of care remained outside its scope. The choice for a projection horizon that is not very far into the future was motivated by the uncertainties about future trends that affect more distant projections.

A cell-based simulation model was developed to answer the research question (see below), which is not fundamentally different from the models

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2) *www.stats.oecd.org; theme: Health > Health expenditure and financing > Health expenditure by function and Health expenditure by provider. Retrieved on 20 April 2012.*

that are used in simular studies in other countries. Yet, it presents some original features, which make it of interest to an international audience. This is due to the fact that we could use a large and rich administrative panel database, which includes (anonymized) public health insurance data for a 5% sample of all persons aged 65 and over in Belgium. The projection model includes indicators of five chronic conditions which are important predictors of disability, as well as a rather detailed breakdown of LTC into a number of categories. Also, it is based on the incidence of LTC (transitions into and between the various LTC categories), rather than prevalence rates, which are most often used in LTC projections. When usage patterns are changing, this should produce more adequate results (Barendregt *et al.*, 1994).

As expected, driven by the ageing of the population, the projection results indicate that the number of older persons in residential care in Belgium will rise strongly, by 32% between 2010 and 2025. Alternative scenarios indicate that the projected increase is smaller if the age-specific incidence of some chronic conditions would decline, or if home care could be expanded considerably beyond the increase that is already required by the ageing of the population. Other scenarios about possible changes in the availability of informal care produce results that are very close to those of the base scenario.

This paper is a shortened version of the complete research report (in English), which can be found on http://kce.fgov.be/node/1228.

2 LITERATURE REVIEW

The construction of the projection model involved an analysis of the determinants of the use of institutional care. Therefore, we reviewed not only the literature on projection models, but also that on predictors of instutional care. We start with the latter. We refer to the research report for a description of the literature search and an extended version of this review.

2.1 Review of studies on institutionalization among older persons

The voluminous literature on this topic has recently been reviewed in Gaugler *et al.* (2007) and Luppa *et al.* (2010a). We also looked at a number of, mostly very recent, studies which had not been included in those reviews (including Connolly and O'Reilly, 2009; Kasper *et al.*, 2010; Kendig *et al.*, 2010; Luppa *et al.*, 2010b; Martikainen *et al.*, 2009; Noël-Miller, 2010; Sarma and Simpson, 2007). Nearly all studies concern a single country, and focus mostly on individual predictors. There is not much attention for the impact of national systems of long-term care.

Most studies use the theoretical framework of Andersen (1968, 1995), which divides predictors into predisposing, need and enabling variables. Among the predisposing variables, the impact of age on the chances of institutionalization appears well-established (Gaugler *et al.*, 2007); Luppa *et al.*, 2010a). Entry rates into nursing homes increase strongly with age, even when controlling for health, functional impairments and living situation. Regarding other predisposing variables, including sex (Luppa *et al.*, 2010a), education (Gaugler *et al.*, 2007) and level of urbanization (Nihtilä and Martikainen, 2007), results are either inconsistent across studies, or based on too few studies to draw definite conclusions.

Need variables refer mostly to physical and mental health. Functional impairment resulting in limitations in Activities of Daily Living (ADL) is a very important predictor of institutionalization (Luppa *et al.* 2010; Gaugler *et al.* 2007; Harris and Cooper, 2006; Kasper *et al.* 2010; Luppa *et al.*, 2010b; Noël-Miller, 2010), whereas the evidence is less clear-cut regarding Instrumental Activities of Daily Living (IADL) limitations (Luppa *et al.*, 2010a, Cai *et al.*, 2009; Kendig *et al.*, 2010; Muramatsu *et al.*, 2007; Noël-Miller, 2010). Persons who are cognitively impaired have a higher probability to enter a nursing home (Cai *et al.*, 2009; Noël-Miller, 2010). The impact of the more specific condition of dementia is particularly strong (Conolly and O'Reilly, 2009; Nihtilä *et al.*, 2007; Luppa *et al.*, 2010a). The evidence for subjective health is more mixed (Luppa *et al.* 2010b; Muramatsu *et al.*, 2007; Cai *et al.*, 2009; Sarma and Simpson, 2007; Gaugler *et al.*, 2007; Noël-Miller, 2010; Kendig *et al.*, 2010). Due to limitations in studies, it is difficult to conclude unambiguously which chronic conditions are most strongly associated with institutionalization. While dementia is the only chronic condition universally acknowledged as a very important predictor of institutionalization, other potential predictors include stroke, diabetes, hip fracture, Parkinson's disease, depression and other mental problems (Gaugler *et al.*, 2007; Luppa *et al.*, 2010a; Harris and Cooper, 2006; Nihtilä *et al.*, 2007; Wong *et al.*, 2010). For the following conditions as predictors of disability, results were less conclusive: heart attack and other cardio-vascular diseases, chronic obstructive pulmonary disease (COPD) and asthma, impaired cognition, hearing impairment, vision impairment, osteoporosis and hypertension (Gaugler *et al.*, 2007; Luppa *et al.*, 2010a; Harris and Cooper, 2006; Nihtilä *et al.*, 2007; Wong *et al.*, 2010).

Among the variables regarded as 'enabling' in the Andersen model, living alone strongly increases the likelihood of entering an institution, particularly for men, while living with a spouse decreases it substantially (Gaugler *et al.*, 2007; Noël-Miller, 2010). The evidence for the impact of other sources of informal help than the spouse, including children, is less conclusive (Gaugler *et al.* 2007; Kasper *et al.*, 2010; Noël-Miller, 2010). Home-owners are much less likely to enter an institution than others (Luppa *et al.* 2010, Gaugler *et al.*, 2007; Cai *et al.*, 2009; Harris and Cooper, 2006; Muramatsu *et al.*, 2007; Sarma and Simpson, 2007). Studies fail to find a clear impact of public or private insurance, income, net worth and other possessions on nursing home entry (Gaugler *et al.*, 2007; Harris and Cooper, 2006; Muramatsu *et al.*, 2007;

Noël-Miller, 2010). Prior nursing home use is a very strong predictor of future nursing home admission (Gaugler *et al.*, 2007; Luppa *et al.*, 2010a).

2.2 Review of projection models

Projection models for LTC have been developed for several developed countries, but apparently by no means for all of them. A clear distinction can be made between single-study models, and models which are the result of a sustained research effort, are regularly updated, and produce a number of projections over time. Examples of the latter are the VeVeRa III model for The Netherlands (Eggink *et al.*, 2009), the Destinie model for France (Duée and Rebillard, 2004; 2006; Le Bouler, 2005), the Dynasim III model for the USA (Johnson *et al.*, 2007), the ASIM III model for Sweden (Lagergren, 2005) and the PSSRU model for England (Wittenberg *et al.*, 2006), from which the model used by the Ageing Working Group for the European Commission (European Commission, 2009; Pickard *et al.*, 2007) is derived. Other studies include Heigl and Rosenkranz (1994), Karlsson *et al.* (2006) and Schulz *et al.* (2004).

The projected time period varies substantially across models and studies. Interestingly, it is often shorter for the large models (e.g. 2005-2030 for VeVeRa III) than for some of the single-study models (e.g. 1990-2050 in Heigl and Rosenkranz (1994)). The choice of horizon is rarely, if ever, explicitly motivated. The large models often incorporate many predictor variables which are difficult to project far into the future. Single-study models, by contrast, are often based on population projections only, which are fairly reliable up to a distant horizon.

Projected variables also vary. Some limit themselves to the number of older persons in disability, which is often regarded as being equivalent to need for care (e.g. Heigl and Rosenkranz, 1994). Others project the number of older persons demanding or using formal care (e.g. Karlsson *et al.*, 2006). Finally, as most models are policy-oriented, costs of care (public or public-plus-private costs) is the variable most often projected. Costs are mostly split up between formal home care and institutional care, sometimes all costs of care are aggregated.

Most projection models are static macro-models, where the population is divided into a number of groups or 'cells', and projections are generated by adjusting the sizes of those cells (e.g. Wittenberg *et al.*, 2006; European Commission, 2009). Dynamic micro-simulation models of LTC (where transitions between states or groups are explictly modelled) are mostly modules or add-ons of dynamic models developed for other purposes (e.g. Duée and Rebillard, 2004; Johnson *et al.*, 2007). All models use data from a variety of sources, as the primary database never contains all necessary data. These databases vary in terms of representativeness and origin of data (administrative or survey).

In order to project future use or costs of LTC, models require projections of the important predictors of LTC, which can be taken from an external source, or produced within the model. The first option is generally chosen for the demographic composition of the population by age and sex. Disability is nearly always projected in a 'static' way using either unchanged prevalence rates by age and sex (and sometimes additional variables), or a logistic equation. The French model 'Destinie' contains dynamic modelling of disability (Duée and Rebillard, 2004). The impact of possible future trends in disability is mostly explored through different scenarios.

Future trends in household situation, in particular the presence of a partner, are often incorporated in the population projections from an external source. The availability of informal care is generally not modelled (except sometimes as an outcome, i.e. informal care use as an alternative to formal care). With one exception, the projections assume a steady state (conditional on background variables) regarding the propensity to provide informal care. The possible impact of changes in the supply of informal care is explored through scenarios.

Given projections of the determinants, the demand for or use of care is projected on the basis of prevalence rates (conditional on those determinants). Alternatively, an econometric (e.g. logistic) equation is used (Johnson *et al.*, 2007). While in most models a distinction is made between formal home care and institutional care, the relationships between these forms of care is not modelled. Some studies explore the possible impact of changes in the relationships between home and institutional care through scenarios (e.g. Wittenberg *et al.*, 2006 ; Le Bouler *et al.*, 2005). Other variables that are sometimes used in the projections are: education, income, housing tenure, ethnicity, degree of urbanization, price of care; exceptionally (at the macro-level) immigration. Nearly all models make the implicit or explicit assumption that the supply of formal care will adjust to match demand, which implies that the projection results are driven by changes in demand (Wittenberg *et al.*, 2006).

2.3 Model results

All studies predict large increases in the demand for formal care, including institutional care, during the coming decades, driven by the ageing of populations (Karlsson *et al.*, 2006; Wittenberg *et al.*, 2006; Lagergren, 2005; Heigl and Rosenkranz, 1994; Schulz *et al.*, 2004; Johnson *et al.*, 2007; Le Bouler, 2005; European Commission, 2009; Woittiez *et al.*, 2009). There is an unresolved debate about past and future trends in disability. Most studies consider a scenario with constant prevalence rates of disability by age and sex categories as too pessimistic (e.g. European Commission, 2009). Most researchers assume that the onset of disability will shift to later ages, though there is disagreement whether this shift will be slower than, equal to, or faster than the expected increase in longevity. These assumptions are equivalent to the expansion of morbidity, the dynamic equilibrium and the contractions of morbidity hypotheses, respectively (cf. Manton *et al.* 2007; Lynch *et al.*, 2009). Different scenarios incorporating different assumptions about future trends in disability result in very divergent projections of long-term care (Wittenberg *et al.*, 2006; Lagergren, 2005; Johnson *et al.*, 2007; Le Bouler, 2005; European Commission, 2009).

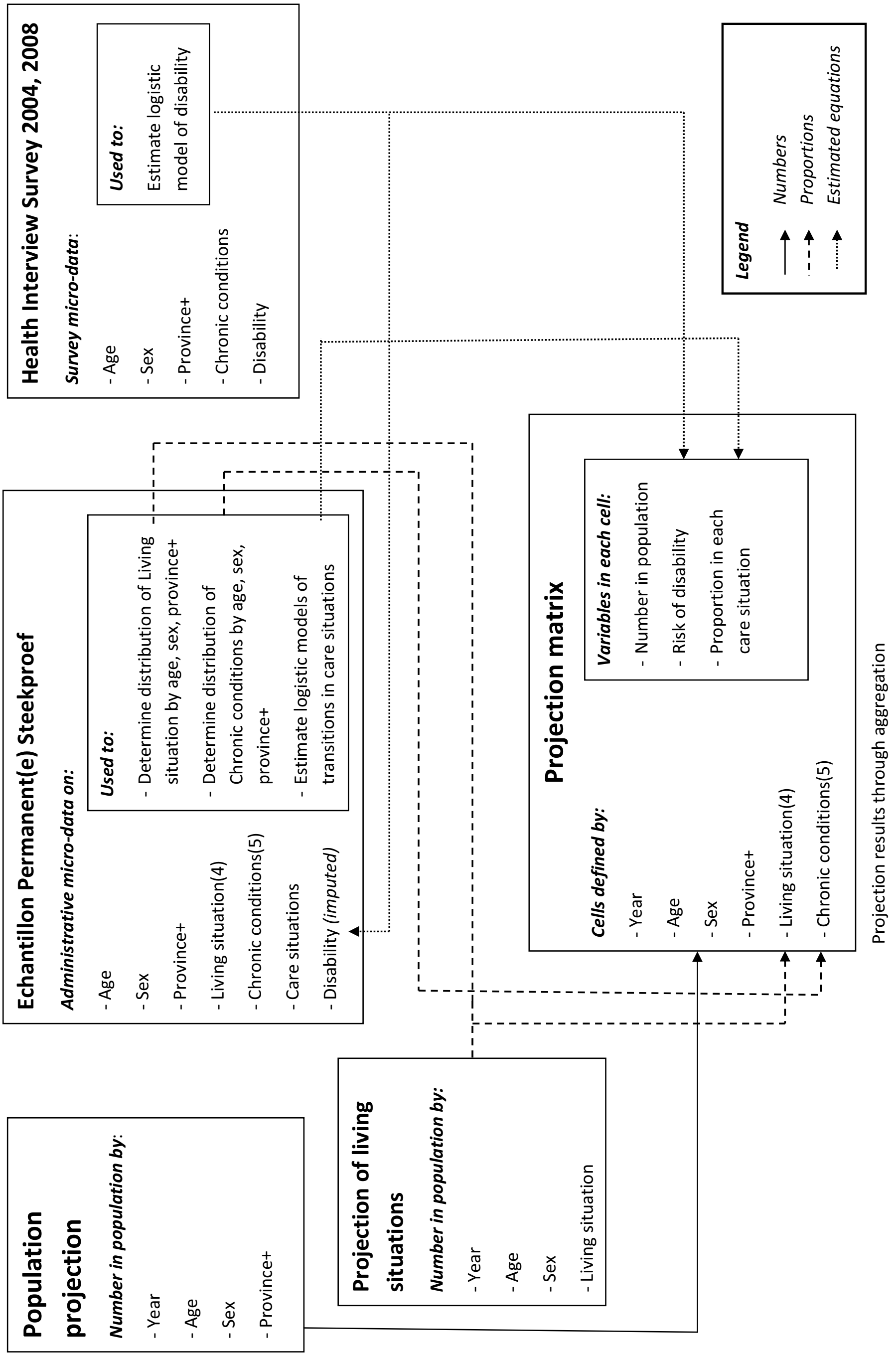
Scenarios where the supply of informal care is changed are mostly hypothetical, making it difficult to judge whether they are in any way realistic. Yet, results show that such changes could have enormous consequences on the demand for formal care (Wittenberg *et al.*, 2006; Le Bouler, 2005; European Commission, 2009). Substitution between various forms of formal care could also have an important impact (Wittenberg *et al.*, 2006; Le Bouler, 2005).

3 RESEARCH METHODOLOGY

The projection model used in this study is a, partially dynamic, cell-based macro-model. Basically, in such models the population is divided into a number of groups or 'cells', by age, sex and other variables. Within each cell, the prevalence of LTC use is determined. By adjusting the size of the groups to, e.g. population projections, applying the prevalence rates within each cell, and aggregating across cells, projections of the overall number of LTC users are obtained. (If total costs are the desired projection outcome, the number of users is multiplied by an estimate of average cost per user.) A basic assumption of such models is that prevalence of use within each cell does not change during the projection period - only the sizes (numbers) of the cells are adjusted. Given this basic set-up, models can vary greatly in complexity, depending on the number of variables and categories used to define the cells, and the way prevalences are determined.

Figure 1 summarizes how the present model was constructed. In the lower middle is the 'Projection matrix' (cells + prevalences) which can be regarded as the 'machine' which produces the projection results. The arrows indicate the sources of the various parts of the machine. Below we will first explain how the numbers in the cells (cell sizes) were determined, and then how the prevalences of LTC within cells were estimated.

Figure 1. Block diagram of projection model



For both purposes, our main database was the 'Echantillon Permanent(e) Steekproef' (Permanent Sample, EPS), a large administrative panel of a sample of all persons within the Belgian public health insurance (Préal and de Vooght, 2009). The latter covers virtually all persons resident in Belgium, certainly among the older population. We used data for persons aged 65 and over only, for whom the sampling fraction is 5%. The EPS contains all information (suitably anonymized) that is available to the public health insurance agencies (the sickness funds and NIHDI, National Institute for Health and Disability Insurance), which includes use of medical care and medicines, as well as some variables related to the socio-economic situation of insured persons. The health status and health problems as such are not registered, though. We use data for the years 2004-09.

3.1 Set-up of the projection matrix

The cells of the projection matrix were defined by the intersection of the following variables:

- age (5-year categories) and sex
- province (some large provinces were split up)
- living situation, described by four variables (presence and availability for informal care of partner, daughter, son, other person)
- five chronic conditions: COPD, dementia, diabetes, hip fracture, Parkinson's disease
- year (2010 - 2025)

The numbers in each cell were derived from a variety of sources:

- The population projections made by the Federal Planning Bureau, in cooperation with ADSEI (Statistics Office), provided the distribution of the population by age, sex and province for each projection year (Bureau Fédéral du Plan, 2011).
- The distribution of living situation by age, sex and province in the base year was derived from the EPS. The proportion of older persons with a partner by age and sex was adjusted across years using projections of living situation by Michel Poulain (2011). These imply that the proportion of older persons with a living partner increases over the projection period, in particular for women aged 80 and over, as life expectancy of men is expected to rise more quickly than that of women, leading to fewer widows.
- The proportions of persons suffering from one or more of the chronic conditions by age, sex and province were derived from the EPS. In the base scenario, it was assumed that these proportion remain unchanged during the projection period. (They are adjusted in some of the alternative scenario's.) It was also assumed that, given age, sex and province, the prevalence of the chronic conditions is unrelated to living situation.

3.2 Estimation of prevalences

Prevalences are estimated seperately for seven LTC situations, of which five are in residential care, and two are in home care, supplemented by three other situations. Within residential care, the Belgian public health care insurance distinguishes five care categories, depending on the number and nature of the ADL limitations of the person concerned, and his or her degree of 'disorientation in space and time'. These are labelled O, A, B, C and Cd. (The short descriptions below are somewhat simplified versions of the actual criteria.) The ten situations are as follows:

- no long-term care, no hospitalization
- home-care use 'low' intensity
- home-care use 'high intensity'
- residential care, cat. O: 0 ADL limitations
- residential care, cat. A: 1-2 ADL lim's *or* 'disoriented'
- residential care, cat. B: 3-4 ADL lim's *or* 'disoriented' and 1-2 ADL lim's
- residential care, cat. C: 5-6 ADL lim's, *not* 'disoriented'
- residential care, cat. Cd: 5-6 ADL lim's *and* 'disoriented'
- hospitalization
- deceased

We observe these situations at the end of each quarter. We chose a quarterly reference period, as spells in residential care of less than a year are not rare.

Transitions between these states were modelled with a hierarchical system of binary and multinomial logistic regressions. Explanatory variables were sex, age, living situation (presence of a partner, daughter, son or other person in the household), province (or part of province) and disability. Disability was not observed in the EPS, but was imputed using a logistic regression equation with age, sex and five chronic conditions (COPD, dementia, diabetes, hip fracture and Parkinson's disease) as right-hand-side variables. The coefficients of the equation were estimated on the basis of the Belgian Health Interview Survey (HIS) data for 2004 and 2008, which include all relevant variables (Van Oyen *et al.*, 1997; Scientific Institute of Public Health, 2012). The selection of the five chronic conditions was motivated by a literature review that showed that these were important predictors of disability, and by the fact that they could be identified reasonably unambiguously by looking at medication or medical care use.

The logistic regression results were used to obtain the prevalences of each LTC category for each cell in the projection matrix, following three steps. First, the risk of disability was imputed, using the equation estimated on the HIS, as described above. Secondly, the incidence of each LTC category for each cell was estimated. Thirdly, the prevalences (percentage of users) of the LTC situations for each cell in the projection matrix were derived in a recursive way from those incidences and the observed initial LTC situations at age 65.

4 FINDINGS AND DISCUSSION

We first present descriptive tables showing the transitions between LTC situations. While strictly not part of the projections, they are a fairly unique by-product of the study. Then we continue with the projection results proper, first discussing the base projection, followed by six alternative scenarios.

4.1 Transitions between LTC situations

Table 1 shows transitions between LTC situations for periods of a quarter, a year and five years. Transition probabilities across a period of one year are calculated starting from the first quarter of each year. The five year part of Table 2 refers to the period 2004 quarter 1 - 2009 quarter 1. Each column of the table shows, for a certain origin state indicated at the top of the column, the proportions of persons that go to various destination states, which are in the rows of the table (after a quarter, a year, and five years, respectively). The situation of "no care" (i.e. no long-term care) is a rather stable situation; even after five years, nearly two-thirds of the persons in this category are still there. The most common exit category is death. Transition probabilities into home care or residential care are rather low.

Persons using home care, especially if it is rather intensive, have a higher chance of moving into residential care than those with no care. It is interesting that a substantial number of persons move from home care directly to the most intensive residential care category (level Cd). There is substantial movement, in both directions, between the LTC situations of home care low and home care high.

Table 1. Transitions in LTC situations after a quarter, one year and five years among persons aged 65+ in Belgium, 2004-09

Quarter	**No care**	**Home care low**	**Home care high**	**Resid. care level O**	**Resid. care level A**	**Resid. care level B***	**Resid. care level C***	**Resid. care level Cd***	**Hospitalization**	**Total**
No care	97,8	5,8	3,6	0,9	0,5	0,4	0,2	0,1	34,2	84,9
Home care low	0,7	85,2	4,3	0,2	0,5	0,4	0,3	0,1	10,5	5,2
Home care high	0,1	2,3	80,6	0,0	0,1	0,2	0,5	0,2	5,6	1,5
Resid. care level O	0,1	0,2	0,1	87,3	4,0	1,3	0,4	0,1	1,9	1,2
Resid. care level A	0,0	0,5	0,3	4,6	79,7	3,7	1,4	0,3	2,6	1,1
Resid. care level B*	0,1	0,8	1,0	2,6	7,4	78,8	3,2	1,5	4,6	1,4
Resid. care level C*	0,0	0,2	0,8	0,8	1,8	3,0	78,6	1,0	3,0	0,7
Resid. care level Cd*	0,0	0,3	1,2	0,5	1,5	6,2	5,8	85,8	4,1	1,8
Hospitalization	0,6	2,4	2,9	1,1	1,3	1,2	1,2	0,8	24,7	1,0
Deceased	0,6	2,0	5,3	2,0	3,4	4,8	8,3	10,1	8,8	1,1
Total	100,0	100,0	100,0	100,0	100,0	100,0	100,0	100,0	100,0	100,0
% in origin category	86,1%	5,2%	1,5%	1,3%	1,1%	1,4%	0,8%	1,8%	1,0%	100,0%

4 quarters	**No care**	**Home care low**	**Home care high**	**Resid. care level O**	**Resid. care level A**	**Resid. care level B***	**Resid. care level C***	**Resid. care level Cd***	**Hospitalization**	**Total**
No care	93,4	7,4	4,4	1,6	0,6	0,5	0,2	0,2	31,8	81,2
Home care low	1,9	66,8	5,9	0,3	0,4	0,4	0,2	0,0	9,5	5,3
Home care high	0,4	5,6	57,6	0,1	0,1	0,1	0,3	0,2	4,8	1,5
Resid. care level O	0,2	0,8	0,2	65,7	7,0	2,3	0,7	0,1	2,7	1,2
Resid. care level A	0,2	1,7	0,7	10,6	49,9	5,8	2,2	0,5	3,2	1,1
Resid. care level B*	0,3	2,6	2,3	6,4	15,8	48,5	5,0	1,9	5,0	1,4

Table 1. Transitions in LTC situations after a quarter, one year and five years among persons aged 65+ in Belgium, 2004-09

Resid. care level C*	0,1	1,0	2,2	2,0	4,4	6,0	48,7	1,4	3,0	0,7
Resid. care level Cd*	0,2	1,5	3,1	1,9	4,7	15,2	12,6	60,2	4,8	1,8
Hospitalization	0,7	2,5	2,1	1,0	1,0	0,9	0,8	0,5	12,9	0,9
Deceased	2,7	10,3	21,4	10,5	16,2	20,3	29,4	35,0	22,4	4,9
Total	100,0	100,0	100,0	100,0	100,0	100,0	100,0	100,0	100,0	100,0
% in origin category	86,1%	5,1%	1,5%	1,3%	1,1%	1,4%	0,8%	1,8%	1,0%	100,0%

5 years (2004/1 - 2009/1)	**No care**	**Home care low**	**Home care high**	**Resid. care level O**	**Resid. care level A**	**Resid. care level B***	**Resid. care level C***	**Resid. care level Cd***	**Hospitalization**	**Total**
No care	73,1	4,9	2,6	0,8	0,1	0,5	0,1	0,0	18,4	64,0
Home care low	4,8	24,2	2,0	0,6	0,1	0,3	0,0	0,0	5,8	5,4
Home care high	1,2	5,9	14,8	0,0	0,0	0,1	0,0	0,2	2,4	1,5
Resid. care level O	0,8	1,3	0,2	21,7	4,1	0,6	0,0	0,0	1,4	1,1
Resid. care level A	0,8	2,5	1,3	8,7	11,0	2,1	0,2	0,2	1,7	1,1
Resid. care level B*	1,0	4,7	2,1	7,5	9,4	8,2	2,0	0,7	3,5	1,5
Resid. care level C*	0,5	2,4	2,7	3,8	3,4	3,9	7,1	1,0	2,5	0,8
Resid. care level Cd*	1,1	4,7	4,2	5,0	7,5	14,1	8,5	12,2	4,3	1,8
Hospitalization	0,8	0,9	0,5	0,5	0,2	0,4	0,3	0,0	4,8	0,8
Deceased	16,1	48,6	69,9	51,5	64,2	69,9	81,8	85,8	55,2	22,1
Total	100,0	100,0	100,0	100,0	100,0	100,0	100,0	100,0	100,0	100,0
% in origin category	86,9%	4,7%	1,3%	1,3%	1,0%	1,2%	0,8%	1,8%	1,1%	100,0%

* both homes for the elderly (MR/ROB) and nursing homes (MRS/ROB)

When in residential care, the probabilities of moving to a higher level of care are substantial, although this is less so for the lowest level (level O) than for the other ones. The probabilities of moving to a lower level are much smaller, and the chances of exiting (other than through death) are quite small. It is striking that the probability of being hospitalized is rather low for persons in residential care, lower even than for those outside LTC, and decreasing with the level of care. Those using home care are most likely to be hospitalized. One must take into account that hospitalization was observed only if there was a stay in hospital of more than 20 days which included the last day of the quarter. Conversely, after such a long spell of hospitalization, many people move or return to residential care. Once persons enter LTC, their risk of dying becomes much stronger. For persons in the most intensive levels of LTC, the chances of being dead after a year are about 1 in 3.

4.2 Projection results: base scenario

It is important to emphasize that projections concern *the demand* for residential care, in the sense of the future use of residential care, provided any possible supply constraints on future use are neither more nor less constraining than today. Obviously, if in the coming years supply of residential care does not follow increasing demand, the projections will not become reality.

The base scenario is based on population projections made by the Belgian Federal Planning Bureau (FPB) and the statistics office (Bureau Fédéral du Plan, 2011). The prevalence of five chronic conditions (COPD, dementia, diabetes, hip fracture, Parkinson's disease) by age, sex and province remains unchanged, which implies that the prevalence of disability itself by age, sex and province is also constant across the projection period. On the other hand, projected trends in household situation were taken into account, which imply an increasing proportion of persons aged 80 and over (mainly women), who are still living with their partner. 3)

The projected number of older persons in residential care rises from 125,500 in 2010 to 166,000 in 2025, which represents an increase of 32% (Figure 2). This rise is almost completely driven by the ageing of the population. The prevalence of being in residential care (i.e. the number of persons in residential care divided by the total number of persons aged 65 or over) is nearly stable, first rising slightly to a maximum of 7.1% in 2017 and then falling during the projection period, so that in 2025 it is practically at the same level (6.8%) as in 2010 (6.7%). This evolution can be explained by reference to the 20th century birth rate history of Belgium. Until 2017, among persons aged 90 and more, the small cohorts born during and around World War 1 are replaced by the larger cohorts born during the subsequent decade. The slight drop in the prevalence rate after 2019 is due to the fact that the relatively smaller cohorts born around the 2nd World War then start to reach the ages where use of residential care is most prevalent.

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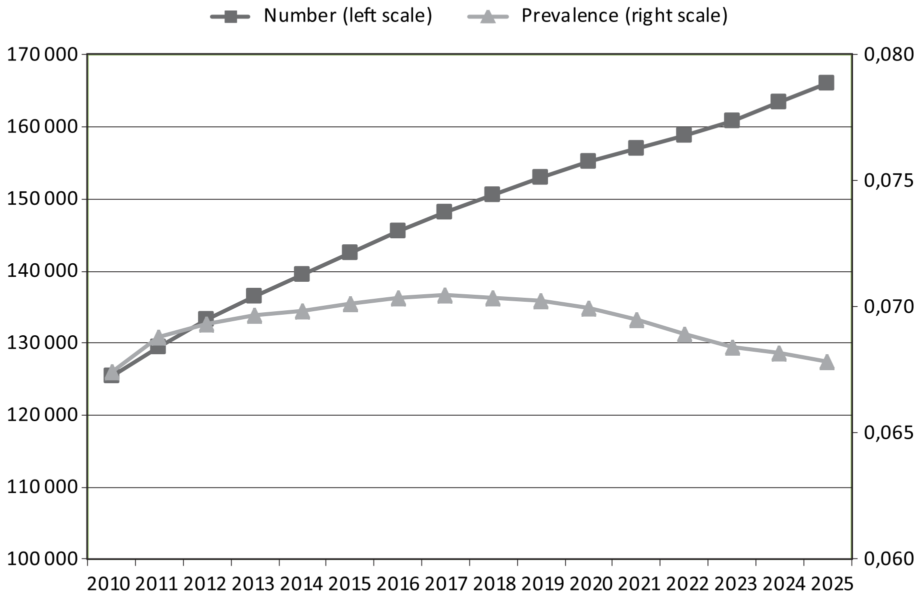
3) *All results are adjusted to take account of the fact that a substantial number of beds in residential care in Belgium are occupied by persons who are not covered by the Belgian public health insurance (mainly foreigners). The assumption is that the proportion of these persons relative to the overall number of users will remain constant across the projection period.*

Figure 2. Projected prevalence and number of older persons in residential care, Belgium 2010-2025, base scenario



However, the composition of persons in residential care by care level will hardly change over time (not shown). There is a small increase in the percentage in the most intensive level (Cd), and at the same time a slight drop in the percentage in the least intensive level O. The proportions in the other care levels remain virtually unchanged. The near-constancy of these proportions follows from the assumption of a constant prevalence by sex and age of the five chronic conditions (and hence of disability itself).

The inclusion of province (or part of province) in the projection variables made it possible to show that the projected increase in the number of older persons in residential care is unevenly spread across provinces (not tabulated). Very strong increases occur in a few provinces (e.g. 87% in Limburg). On the other hand, a decrease is projected for Brussels. The reasons for these divergent developments are demographic. In Limburg for example, less than 10% of all older persons are aged over 85 at the moment, and these provinces will undergo the strongest ageing-within-ageing effect (i.e. an increase in the number of the oldest old). The importance for the planning of additional LTC facilities of such regional differences is obvious.

4.3 Alternative scenarios

In order to show the sensitivity of the projection results with respect to alternative hypotheses, six alternative scenarios were explored, three of which concern disability, two relate to informal care, and one is about home care. Three are more pessimistic than the base scenario and three are more optimistic. They are:

1. The prevalence of chronic conditions declines in line with the increased educational level of each new cohort of older persons
2. The risk of disability by age and sex will decrease in future, in the sense that half of the projected increases in longevity are assumed to be spent free of disability.
3. The prevalence of diabetes will increase by 5% annually during the projection period
4. The household situation of older persons by age and sex group will not change during the projection period
5. The number of children living with their older parents will be halved during the projection period
6. Home care expands by 50% (beyond what is required by the ageing of the population).

The projected trends in the number of residential care users following these scenarios are shown in Figure 3.

4.3.1 Alternative scenarios on disability

Scenario 1: "Better education" involves a significant reduction in the prevalence of chronic conditions in Belgium during the projection period 2010-2025. Two observations motivate this scenario: first, estimations using Health Interview Survey data indicated that the prevalence of most chronic conditions is smaller, within any age-and-sex group, among older persons with more than primary education; second, in every cohort, the proportion of persons with more than primary education is larger than in the previous cohort. This implies that the educational level of older persons in future years will be higher than it is now. Moreover, this trend is reinforced by differential mortality, as those with better education live longer. The decreases in the overall prevalence of these chronic conditions are fairly small, though: e.g., from 11.9% in 2010 to 10.8% in 2025 for diabetes and 5.3% to 4.9% for dementia. Compared to the base scenario, the projected number in residential care in 2025 according to the "Better education" scenario is about 6000 less; representing an increase relative to 2010 of 29%, instead of 32%.

Scenario 2: "Disability compression" assumes that increases in longevity during the projection period are accompanied by a delayed onset of disability. For every year added to life expectancy (at age 65), disability rates are assumed to shift to a later age by half a year. This is the reference scenario of the Ageing Working Group of the EU's Economic Policy Committee (European Commission, 2009). This scenario leads to a substantially smaller projected number of persons in residential care in 2025 than in the base scenario: about 150500, representing an increase relative to 2010 of 21%.

Scenario 3: "Diabetes epidemic" is suggested by recently observed trends for Belgium (Instituut voor Farmaco-Epidemiologie van België, 2007) and abroad (UK, Germany, Italy and France) (Passa, 2002). Currently, it is impossible to obtain robust data about the trend in the prevalence of diabetes in Belgium. So, the prevalence is estimated through diabetes medication (in terms of Defined Daily Doses), knowing that not all diabetic patients take medication. We assume an overall increase in diabetes prevalence by 5% per year between 2010 and 2025, and this increase occurs uniformly in all sex-and-age groups. This means that the prevalence of diabetes will more than double during the projection period, up to 26% in 2025. By contrast to the previous two scenarios, this scenario implies an expansion of morbidity. The impact on projected numbers in residential care is small though: only 3400 more than in the base scenario; representing an increase relative to 2010 of 35%.

4.3.2 Alternative scenarios on household situation

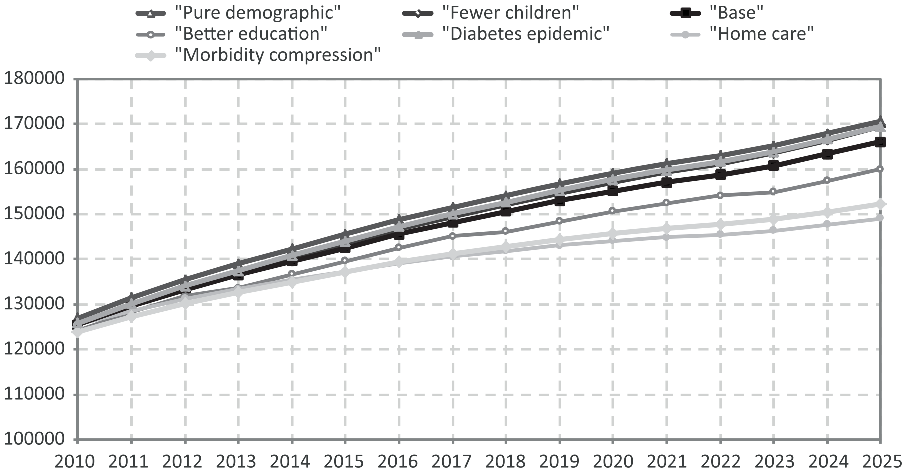
Scenario 4: A "Pure demographic scenario" supposes that the household situation (the presence of a partner, children and/or other household members) within any sex-age group does not change over the projection period. This scenario is more pessimistic than the base scenario, since the latter incorporates the expectation that the proportion of persons aged 85 and more with a living partner will increase. The impact on projected numbers in residential care is small though: only 4600 more than in the base scenario; representing an increase relative to 2010 of 35%.

Scenario 5: The scenario "Fewer children" hypothesizes that fewer children will live in the same household as their parents. Concretely, within any sex-age group, the number of older persons living with their children will drop by half over the projection period. This (pessimistic) scenario is included to show the sensitivity of the projection results to a change in the availability of informal care provided by persons other than the partner. Again, the impact on projected numbers in residential care is quite small: only 3400 more than in the base scenario; representing an increase relative to 2010 of 35%.

4.3.3 Alternative scenario on home care

Scenario 6: In order to provide an estimate of the possible impact of an expansion of home care, we assumed that the additional home care is equivalent to the care given by a partner, i.e. has the same impact on the probability to enter an institution. The simulated additional home care is targeted to single persons with a probability of disability of at least 5%. The results of a model of the transition to home care indicates that this is in fact a threshold above which older persons are much more likely to start using home care. Fairly arbitrarily, we assumed an expansion of home care by 50%, in addition to the increase that is required already by the ageing of the population. In this scenario, the projected number of old people in residential care would be considerably lower (about 17,000 less) than in the base scenario. Relative to 2010, the increase would be only 23%. This result indicates that very large changes are required in the supply of home care in order to substantially reduce the projected growth in the number of persons in residential care.

Figure 3. Projected trends in the number of older persons in residential care, Belgium 2010-2025, according to various scenarios.



5 CONCLUSIONS

This study projects a strong rise of the number of users of residential care in Belgium from about 125,500 currently (aged 65 or older), to about 166,000 in 2025, an increase of about 32%. The main driver of this development is the expected demographic ageing of the Belgian population. The study looked at the sensitivity to alternative assumptions about disability and living situation. Regarding the latter, it was found that realistic scenarios about the presence of partners or children in the household do not make much difference. However, we assume an unchanged willingness to provide informal care from partners in particular. As regards disability, the results indicate that if the prevalence of five important chronic conditions would go down in line with the higher education level of future cohorts of older persons, this would have only a limited effect on the projected number of users of residential care. However, if increased longevity would be accompanied by a shift of the onset of disability to later ages, the increase in the projected number of persons in residential care would be significantly lower. An obvious alternative to residential care is home care. However, we found that if home care would be expanded by 50 percent - beyond the increase that is required already to keep up with the ageing population - the number of users of residential care would still be increase by 23%.

What is the added value of the projection model presented in this paper? Given that ageing is the dominant driver of the projected increase in the use of residential care, one might question whether it was worth the effort to create this complicated machinery, as a much simpler model could have produced quite similar results. However, previous LTC projection exercises based on population projections alone were often criticised for failing to take account of future developments in the prevalence of disability and in living situation, and doubts were expressed whether the large projected increases in the demand for formal LTC would actually materialize. The results of the alternative scenarios that could be worked out with this model show that such doubts are only partially justified, at least for the medium term in Belgium: even when fairly optimistic assumptions are made about future developments in the prevalence of disability and in living situation, the projected increases in the use of residential LTC are still substantial.

The model also has its limitations, partly due to gaps in the data, and partly due to insufficient scientific knowledge. Disability could not be directly observed in the main database used but had to be imputed; also absent were indicators of the availability of informal care from outside the household, and of home tenure. (The literature review revealed that home owners are much less likely to enter residential care than tenants.) In the future, these gaps in the data might be filled by linking various administrative databases, or matching survey data to administrative data, if technical and legal problems could be overcome. An important source of uncertainty in our projections (as in those of other researchers) is the lack of reliable projections for the coming decades of the prevalence of disability and important chronic diseases.

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UNMET SUPPORTIVE CARE NEEDS OF LUNG CANCER PATIENTS DURING THE CHEMOTHERAPY PHASE: A DESCRIPTIVE STUDY

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ABSTRACT

Problem: To date evidence on supportive care needs of lung cancer patients during treatment is sparse. If health care providers want to ensure that these patients' physical, informational, psychological and emotional as well as sexual needs are met, they need to know their supportive care needs in more detail.

Aim: The goals of this study were (a) to describe the unmet supportive care needs among patients suffering from lung cancer during the chemotherapy phase at a university hospital in Switzerland and (b) to explore a potential relation between unmet supportive care needs and the patient's age, gender and smoking cessation after diagnosis.

Method: The study employed a descriptive design. Patients were recruited in the outpatients' and inpatients' oncological clinics of a university hospital in Switzerland following a non-probability sampling method. Unmet needs were measured with the Supportive Care Needs Survey Short Form 34 (SCNS SF 34) which comprises 34 items - categorized in five domains (psychological, health system and information, physical and daily living, patient care and support, and sexuality needs). For each item, respondents report the level of need they have (no need, need satisfied, low need, moderate need or high need). Data were collected through two self-administered questionnaires (SCNS SF 34 and a socio-demographical questionnaire), and from patients' records (medical data).

Results: Thirty-seven patients were included in the study. Results show that the most relevant unmet needs among patients were those related to the psychological, physical/daily living and informational domains. The most prevalent unmet supportive care needs were: "Uncertainty about the future" (70.3%) followed by "Being informed about things you can do to help yourself to get well" (64.8%). The results emphasize that 11 items were not met for at least 50% of the patients. With respect to differences in dissatisfaction in relation to gender, age and smoking cessation after diagnosis, we did not find significant correlations.

Conclusion: The results of our study showed that patients with lung cancer have a high degree of unmet supportive care needs linked to the psychological, physical/daily living and informational domains. Age, gender, and smoking cessation was not shown to correlate significantly with total supportive care needs or any of the four subscales of the SCNS SF 34. Nevertheless, our results indicate that many supportive care needs for lung cancer patients go unmet in more than 50% of the patients and efforts to meet them are needed. We are currently investigating the development of interventions to better meet the needs of this population.

KEYWORDS

lung cancer, needs assessment, oncology, supportive care needs

1 INTRODUCTION

In Switzerland, around 2500 males and 1200 females are newly diagnosed with lung cancer each year. Lung cancer is considered the second most frequent cancer for males (13%) and the third for females (8%). Prevalence increases with age, and is highest between 50 and 75 years (Office fédéral de la statistique, 2011a). The Federal Statistical Office (2011b) estimates that in terms of mortality, lung cancer will become the most frequent oncological cause of death for males and females. Compared to other major cancers, lung cancer has a low survival rate of 14% at five years. In spite of considerable advancement in multimodal cancer treatment, no significant decline in this cancer-specific mortality has been observed so far. Many tumours are discovered at a late stage, partially due to the current status that no routine screening for lung cancer is recommended (Mohan *et al.*, 2007; Yarbro *et al.*, 2010).

Lung cancer patients suffer from more physical and psychological symptoms caused by the disease and the sides effects of the oncological treatment (chemotherapy, radiotherapy and surgery) than patients with other major cancers. The highest symptom prevalence has been observed for dyspnoea, cough, fatigue, anorexia, pain, insomnia, anxiety and depression (Brintzenhofe-Szoc *et al.*, 2009; Cooley *et al.*, 2003; Joyce *et al.*, 2008).

Recently, studies investigated links between smoking behaviour and the experience of lung cancer patients, showing that smoking patients recognized lung cancer as a self-inflicted disease, and experienced discrimination and stigmatization by society (Chapple *et al.*, 2004; LoConte *et al.*, 2008).

Due to severe symptoms and their unfavourable prognosis, lung cancer patients have specific supportive care needs that should be assessed and met by a multidisciplinary cancer team. The Multinational Association of Supportive Care in Cancer defines supportive care as "the prevention and management of the adverse effects of cancer and its treatment. This includes management of physical and psychological symptoms and side effects across the continuum of the cancer experience from diagnosis through anticancer treatment to post-treatment care. Enhancing rehabilitation, secondary cancer prevention, survivorship and end of life care are integral to Supportive Care"(Meili, 2011).

A growing body of research focuses on the psychosocial needs of cancer patients. Needs assessments directly assess and identify specific issues of need for patients, taking into account the whole perceived cancer experience (Sanson-Fisher *et al.*, 2000; Sutherland *et al.*, 2009). In fact, patient-centred care is unlikely to occur without a good understanding of patient needs and influencing factors. An assessment of patients' perceived supportive care needs makes it possible to identify the intensity of need and prioritize service needs. Such an approach allows for the individualized allocation of resources in order to prevent or at least to reduce problems through appropriate early interventions (Bonevski *et al.*, 2000; Richardson *et al.*, 2007).

2 LITERATURE REVIEW

During the past decade, there have been several studies focused on assessment of unmet supportive care needs, reflecting the multidimensional impact of cancer. Cancer patients have reported high levels of unmet need related to issues such as provision of information, psychosocial support, practical assistance and sexual issues (Carey *et al.*, 2012). However, lung cancer patients seems an underexplored population. A search in CINAHL and PUBMED yielded three studies assessing the supportive care needs of this specific population (Fitch & Steele, 2010; Li & Girgis, 2006; Sanders *et al.*, 2010). Many assessments of supportive care needs focused on cancer patients in general at different stages of the disease or specifically on breast cancer patients (Carey *et al.*, 2012; Harrison *et al.*, 2009). The few studies focusing on the needs of lung cancer patients suggest that lung cancer patients have significantly more unmet supportive care needs than other patient groups (Li & Girgis, 2006). Results showed also that patients living with lung cancer reported especially high unmet supportive care needs in the psychological and physical and daily living domains (Fitch & Steele, 2010; Li & Girgis, 2006; Sanders *et al.*, 2010). To our knowledge, no needs assessment of lung cancer patients in the Swiss health care system has been conducted. To improve high quality care including patient self-determination, needs assessment are among the prioritized goals of the national cancer programme (Meili, 2011).

The goals of this study were (a) to describe the unmet supportive care needs among patients suffering from lung cancer during the chemotherapy phase at a university hospital in Switzerland and (b) to explore a potential relation between the unmet supportive care needs and the patient's age, gender and smoking cessation after diagnosis.

3 METHOD

Sample and setting

We conducted a descriptive study by means of a cross-sectional survey in a Swiss university hospital. Patients were recruited in the outpatients and inpatients oncological departments following a non-probability consecutive sampling method. Adult lung cancer patients that were undergoing chemotherapy treatment between January 2011 and February 2012 with a 5-month break (April-August 2011) were invited to participate in the study. Patient eligibility criteria included being registered at the hospital as lung cancer patients (NSCLC or SCLC), at least eighteen years of age, diagnosed 16 weeks prior, under chemotherapy treatment, capable of speaking and writing in

French and physically and mentally able to complete the questionnaire. This study was approved by the cantonal ethics committee (174/10).

Procedure

The oncologist of each patient met patients during a post-chemotherapy consultation and explained the study objectives and methods, and then handed out two questionnaires with a stamped return envelope to patients. An accompanying cover letter was used to remind patients of the main study goal. Participants who did not return the questionnaires after 3 weeks received a follow-up telephone call from the researcher.

Measures

We used the Supportive Care Needs Survey, short form comprising 34 items (SCNS-SF34) (Bonevski *et al.*, 2000). The purpose of the SCNS-SF 34 instrument is to provide a direct and comprehensive assessment of the multidimensional impact of cancer on the needs of cancer patients. The development and assessment of the survey's psychometric properties, including a list of survey items, are fully described in the user's guide (McElduff *et al.*, 2004). The SCNS SF 34 asks patients to indicate their level of supportive care needs, with issues grouped into 5 main domains: psychological (PS), health system and information (HIS), physical and daily living (DL), patient care and support (PC) and sexuality needs (S). Each item is preceded with the stem question, "In the last month, what was your level of need for help with …?" Importance of needs is rated on a 5-point Likert scale (not applicable=1; satisfied=2; low need=3; moderate need=4; high need=5). Translation from the English version of SCNS SF 34 to a French version assessed the reliability of the SCNS-SF34 questionnaire for the five domains as a 0.7 Cronbach's alpha score, which is considered the minimum score for the questionnaire to be considered as reliable (Griesser *et al.*, 2010).

Socio-demographic variables were measured by an additional survey exploring family situation, country of origin, education and other related socio-demographic factors.

Medical data were based on medical records.

Statistical analyses

Descriptive statistics used STATA ® version 11. To identify the level of patients' dissatisfaction for each domain of SCNS SF 34, we calculated a mean, median score (Md), standard deviation (Sd) and minimum and maximum (Min and Max) for each domain of the survey, and standardized final scores on a scale from 0 to 100. The maximum possible score was 100 (high needs) and the lowest score 0 (no needs) (McElduff *et al.*, 2004). To identify more specifically which supportive care need was unmet, we dichotomized each item of SCNS SF 34 to create two variables for each item (1- 2 points on Likert scale = no need) and (3-4-5 points on Likert scale = unmet needs) (McElduff *et al.*, 2004). We used frequency distributions to show needs that were not met for at least 50% of patients. A Wilcoxon rank-sum test was used to test if gender, smoking cessation after diagnosis and age (Spearman test) was associated with level of supportive care need. Significant predictors were identified as those with a p-value < 0.05 in the final model.

4 RESULTS

Participant

Of 220 eligible patients, 106 were approached by doctors and 37 agreed to participate in the study. In total, 37 patients sent back the questionnaire. Patients who refused to participate in the study were fatigued or not interested in the study participation.

Socio-demographic and medical data

Table 1 provides details on the main characteristics of patients. We found that 91.8% of patients were less than 75 years old and gender was equally divided. Thirty-five per cent had completed obligatory education and 45% an apprenticeship-level education. Based on the Tumour Node Metastasis classification system and The Veterans Administration Lung Group classification, 78.4% were identified as having a NSCLC and 21.6% SCLC. Sixteen per cent of patients did not smoke and among smokers, 48.4% had stopped smoking after diagnosis.

Hierarchy of unmet needs

Table 2 describes the hierarchy of patients' needs. The results showed that 11 items were not met for at least 50% of patients. The two most prevalent unmet supportive care needs were: "Uncertainty about the future" (70.3%) followed by "Being informed about things you can do to help yourself to get well" (64.8%). Among 11 items that were not met for at least 50%, we found no items linked to sexual (S) or patient care and support (PC) needs, and only one item linked to physical and daily living: "Not being able to do the things you used to" (59.5%).

Domains of supportive care needs

Across the five domains in the SCNS-SF 34, participants reported the highest level of need for help with psychological needs (Md= 47.5), followed by physical and daily living needs (Md= 40), health system and informational needs (Md= 36.4), patient care support needs (Md= 30) and sexuality needs (Md= 16.7) [Table 3].

Relation between the unmet supportive care needs and the patient's age, gender and smoking cessation after diagnosis

Age, gender, and smoking cessation were not shown to be significantly associated with total supportive care needs or any of the five subscales of the SCNS-SF 34.

5 DISCUSSION

This study highlights the high level of psychological (Md= 47.5), physical (Md= 40) and informational (Md= 36.4) unmet supportive care needs among lung cancer patients undergoing chemotherapy treatment. These findings suggest that unmet supportive care needs are common across individuals with lung cancer. Age, gender and smoking cessation did not correlate with unmet supportive care needs.

More than half of all patients expressed an interest in services related to information linked to self-care management at home. In fact, 64.8% (rank 2) patients expressed dissatisfaction concerning "Being informed about things you can do to help yourself to get well" and 59.5% (rank 4) concerning "Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home". One possible reason is that the level of educational background in the sample was low (35.2%) or medium (45.9%) which has been described as a factor predicting unmet needs linked to the informational domain (Mills & Sullivan, 1999). Nevertheless, our results differ substantially from those of other international studies in the field (Li & Girgis, 2006; Sanders *et al.*, 2010) and might therefore underline the importance of providing personalized information and education to patients. Another interesting finding was that their level of sexual needs was not expressed as unmet by the majority of patients. Indeed, several studies showed that a high level of sexual needs was associated with a high level of symptoms (nausea, vomit, dyspnoea, pain) (Shell, 2008; Shell *et al.*, 2008; Tierney, 2008). Potentially, patients had unmet needs in the sexuality domain but those kind of needs were not a priority in this phase of their illness trajectory.

High levels of physical and daily living needs could be linked to side effects of chemotherapy and symptoms of disease such as fatigue, pain, sleep disturbance and dyspnoea (Cooley *et al.*, 2003; Davidson *et al.*, 2002; Henoch *et al.*, 2008; Joyce *et al.*, 2008). High levels of psychological needs could be explained by the influence of unfavourable prognoses, which could cause more psychological distress than other cancers, and the negative effect of high levels of physical needs on the psychological domain, 28-30. As our medical data show, a high proportion of patients had an advanced stage of disease (54.1% III/IV) so that the additional burden caused by symptoms and unfavourable prognoses may have influenced the results. Our results regarding high levels of psychological and physical needs are in accordance with the three similar studies focusing on assessment of supportive care needs in lung cancer patients. In contrast though, in our study, patients expressed high levels of unmet informational needs that had not been observed elsewhere (Fitch & Steele, 2010; Li & Girgis, 2006; Sanders *et al.*, 2010).

This study did not show any evidence of a relationship between unmet supportive care needs and the patient's age, gender or smoking cessation after diagnosis. Concerning age and gender, our results are in accordance with a previous study of 109 lung cancer patients (Sanders *et al.*, 2010). In contrast, previous studies observed an association of distress and quality of life with gender and age (Chan, Richardson, & Richardson, 2011; Graves *et al.*, 2007). To date, few studies have focused on a possible association between needs and smoking habits in lung cancer patients. Further research is needed since perceived cancer-related stigma in lung cancer patients is higher than in prostate and breast cancer patients higher than in prostate and breast cancer patients (LoConte *et al.*, 2008). This might impact their willingness or ability to express needs to health professionals.

Our study has several limitations. First, our sample size was too limited to generalize results or to use parametric statistical tests. Recruitment proved particularly difficult in this patient population. The sample is therefore small (37 patients). Secondly, a non-probability consecutive sampling method has several limitations in terms of the representativeness of the target population. Finally, as the study was performed in a single university hospital, our study findings may lack generalizability to other settings.

In terms of practical implications of our findings, we point out the importance of improving supportive care for lung cancer throughout chemotherapy phase by targeting patients' physical, psychological and informational needs. We suggest integrating the Supportive Care Needs Survey Screening Tool 9 with existing care, so as to identify and address unmet supportive care needs (Girgis *et al.*, 2011). Concerning the importance of providing personalized information and education to patients, our results showed that patients need to be educated on management of symptoms, which could be provided in a pre-chemotherapy education intervention on patient distress, symptom burden, and treatment (Aranda *et al.*, 2011). Furthermore, the promotion of coping strategies offered by health professionals could also improve the patients' self-efficacy to cope with symptomatology and their physical well-being (Rueda *et al.*, 2011). More research examining longitudinal changes of supportive care needs and the integration of interventions to meet lung cancer patients' needs is strongly recommended. Additional studies would enable us to investigate the relationship between smoking and supportive care needs with a larger sample.

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Table 1. Demographic and medical characteristics of participants

Variable		*M (SD)*	n (%)
Gender	Male		19 (51.3)
	Female		18 (48.7)
Age		61.4 (8.7)	
Age (years)	<55		7 (18.9)
	55-64		19 (51.3)
	65-74		8 (21.6)
	75-84		2 (5.5)
	>85		1 (2.7)
Area of residence	City		25 (67.6)
	Countryside		12 (32.4)
			13 (35.2)
Level of education	Obligatory education		17 (45.9)
	Apprenticeship		7 (18.9)
	University, graduate school		
Diagnosis	NSCLC		29 (78,4)
	SCLC		8 (21,6)
	I/II		9 (24,3)
Stage of disease	III/IV		20 (54,1)
	Limited		5 (13,5)
	Extensive		3 (8,1)
Smoking before diagnosis	Yes		31 (83.8)
	No		6 (16.2)
Smoking cessation after diagnosis	Yes		15 (48.4)
	No		16 (51.6)

Table 2. 11 needs that were not met by at least 50% of the patients (n= 37)

Rank	Need (Item of SCNS SF 34)	Domain	Unmet need* n (%)
1	Uncertainty about the future	PS	26 (70.3)
2	Being informed about things you can do to help yourself to get well	HIS	24 (64.8)
3	Anxiety	PS	23 (62.2)
3	Worry that the results of treatment are beyond your control	PS	23 (62.2)
4	Not being able to do the things you used to	DL	22 (59.5)
4	Feeling of sadness	PS	22 (59.5)
4	Learning to feel in control of your situation	PS	22 (59.5)
4	Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	HIS	22 (59.5)
5	Fears about the cancer spreading	PS	21 (56.8)
5	Concerns about the worries of those close to you	PS	21 (56.8)
6	Having access to professional counselling (e.g. psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it.	HIS	19 (51.4)

Note. DL : Physical and daily living / PS: Psychological / HIS : Health system and information (HIS)

* dichotomized each item of SCNS SF 34 on Likert scale (1- 2 = no need) and (3-4-5 = unmet need).

Table 3. Level of dissatisfaction about supportive care needs for each standardized domain of SCNS SF 34 (n. 37)

Domain	Md	M	Sd	Min-Max*
Psychological (PS)	47.5	46.3	20.9	7.5 - 82.5
Physical and daily living (DL)	40	41.2	19.8	10 - 90
Health system and information (HIS)	36.4	39.12	18.2	6.8 - 97.8
Patient care and support (PC)	30	33.2	21.6	0 - 100
Sexuality (S)	16.7	22.8	30.5	0 - 100

*Possible values ranging from zero to 100.

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Congress Papers

RELATIONSHIP BETWEEN SELF-CARE AGENCY, SELF-CARE PRACTICES AND OBESITY AMONG RURAL MIDLIFE WOMEN

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ABSTRACT

Purpose: To examine the relationship between self-care (SCA), self-care practice (SCP), and obesity among rural midlife women. Background: Obesity is a world-wide health concern. Self-care practices are linked to obesity reduction, yet no prior studies of the relationships between self-care and obesity among rural midlife women were identified. This study applied Orem's Self-Care Deficit Nursing Theory and Rural Nursing Theory as the theoretical frameworks. Method: A predictive correlational design was used. Participants completed demographic and basic conditioning factors (BCFs) data, Denyes Self-care Agency Instrument (DSCAI-90©) and Denyes Self-care Practice Instrument (DSCPI-90©). Anthropometric measurements were height and weight. A predictive model of self-care in rural midlife women was constructed based on Orem's theory and rural nursing theory. Results: Participants were 224 ambulatory rural women, ages 40-64 years, from 10 northern counties of an upper plains state. Mean age was 52 years. Mean body mass index (BMI) was 29.2. Education and health status were facilitators to SCA with smoking as a barrier. Education, employment and health status were identified as facilitators of SCP with smoking and chronic illness as barriers. Self-care agency predicted self-care. The hypothesized model was tested and revised. BMI had the greatest direct effect on SCA. Self-care agency had the greatest direct effect on SCP. No significant relationship was found between SCA, SCP and distance to healthcare provider. A negative relationship was found between chronic diseases and

SCP, but not SCA. Qualitative data identified the meaning of health, self-care and impact of distance on access to healthcare in rural midlife women. Conclusion: By capitalizing on the facilitators and minimizing the barriers to SCA and SCP, nursing may tailor interventions to address obesity. The model suggested new knowledge of the relationships of SCA, SCP and BMI in rural midlife women.

KEYWORDS

midlife women, obesity, Orem, rural, self-care

1 INTRODUCTION

The United States (U.S) is experiencing a health crisis. The obesity rates exceed 25% in 38 states with two-thirds of adults obese or overweight (Levi *et al.*, 2011). The prevalence of obesity in South Dakota has increased in the last five years from 23.8% to 30.2% (The United Health Foundation *et al.*, 2010).

The economic burden of obesity is a national, state and global concern. The national health care expenditures for 2008 totalled $2.34 trillion dollars (U.S. Census, 2011). U.S. could spend over $343 billion on health care costs for obesity if current trends continue for the next ten years (Thorpe, 2009). South Dakota's obesity median attributable health care spending in 2008 was $220 million with the potential to reach $398 million by 2013 if current trends continue (Thorpe, 2009).

Obesity related costs for 10 European countries ranged from 0.09% to 0.61% of national gross domestic income (Müller-Riemenschneider *et al.*, 2008). A Canadian review identified the direct cost for overweight and obesity at $6 billion or 4.1% of total health care expenditures in 2006 (Anis *et al.*, 2010). Taiwan's excess medical expenditures attributed to overweight and obesity in 2001 were NT$30.1 billion or approximately 8 % of total medical expenditures (Hu *et al.*, 2008).

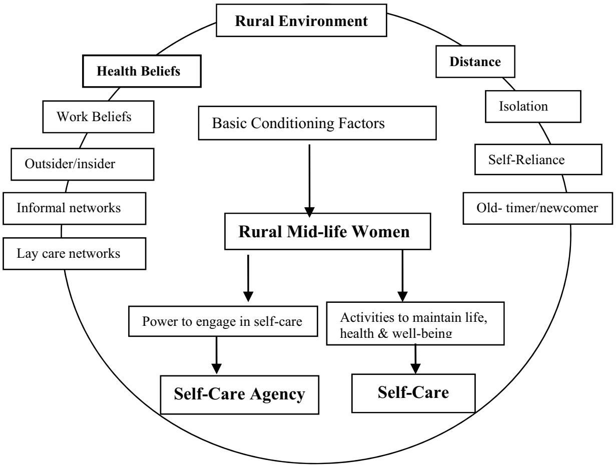
The purpose of this non experimental, predictive correlational study was to examine the relationship between self-care agency (SCA), self-care practices (SCP), and obesity in rural midlife women. Barriers and facilitators to SCA and SCP were examined. A causal model, self-care in rural midlife women, was hypothesized and tested.

Dorothea Orem's self-care theory and rural nursing theory provided the theoretical framework for the study. Self-care is the central concept of the self-care theory. Self-care is defined as "the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being" (Orem, 2001, 43). Self-care agency as defined by Orem is "the complex acquired capability to meet one's continuing requirements for self…." (Orem, 2001, 245). Self-care agency and self-care are influenced by basic conditioning factors (Orem, 2001).

Rural nursing theory is a developing middle-range theory. Long and Weinert (1998) identified the need for a framework for nursing practice to meet the health care needs of rural persons. The key concepts are work beliefs, health beliefs, isolation, distance, self-reliance, lack of anonymity, outside/insider, old timer/newcomer, informal networks, lay care networks, familiarity and professional isolation (Long & Weinert, 1998).

With rural midlife women at the center, the rural environment envelops with the key concepts and basic conditioning factors (BCFs) influencing engagement in self-care agency and self-care practices (Figure 1).

Figure 1. Self-care agency and the rural environment. Adapted from Denyes, *et al.*, (2001) and Lee, H. and Winters, C. (2006).



2 LITERATURE REVIEW

A critical literature review provided insight into women's views of self-care and the process of self-care actions. Studies explored the concept of self-care, SCA, and SCP in white non-Hispanic middle-aged women and Latinas in the United States and women in Pakistan, Taiwan, and Thailand (Arpanantikul, 2006; Hartweg, 1993; Hartweg & Isabelli-Garcia, 2007; Lee, 1999; Mendias *et al.*, 2001; Sánchez, 2007; Wang, 2001; Wang and Laffrey, 2001). Medias *et al.,* (2001) identified self-care practices as actions to promote self-care for health or wellness. Qualitative research with first and second generation, low-income, Spanish speaking women identified self-care themes related to nutrition, exercise, and seeking medical care (Hartweg and Isabelli-Garcia, 2007).

Lee (1999) examined relationships among BCFs, SCA, self-care and six health outcomes in Pakistani women. BCFs of education, and freedom of movement had a positive influence on self-care, while number of male children and ethnic group had a negative effect on self-care.

Education was found to be significantly correlated and/or predictive of self-care agency and self-care (Campbell and Soeker, 1999; Campbell and Weber, 2000; Lee, 1999). The positive correlation between education and SCA is consistent with Orem's theory. Hurst et al (2005) found education either negatively or not significantly correlated with self-care agency or self-care.

The literature review identified age as significantly correlated and/or predictive of self-care agency (Baker and Denyes, 2008; Campbell and Weber, 2000; Slusher, 1999; Wang and Laffrey, 2001; Wang, 2001). However studies also showed that age was negatively or not significantly correlated with self-care agency or self-care (Anderson, 2001; Campbell and Soeker, 1999; Hurst et. al., 2005; Wang, 2001).

Self-care agency was identified as a predictor or promoter of self-care (Anderson, 2001; Baker and Denyes, 2008; Denyes, 1988; Lee, 1999; Mendias *et al.*, 2001; Wang, 2001; Wang and Laffrey, 2001). Two studies reported a positive association between SCA and health promoting lifestyle (Wang, 2001; Wang and Laffrey, 2001). Owen (2007) identified higher SCA in postmenopausal women participating in a mall walking program.

Denyes (1988) found in her classic study that SCA and self-care were predictors of general health state. Other studies confirmed that SCA and self-care were predictors of health state (Anderson, 2001; Campbell and Soeker, 1999; Frey and Denyes, 1989; Lee, 1999).

Basic conditioning factors (BCFs) are factors or characteristics that influence self-care agency and self-care (Denyes, 1988; Orem, 2001). Basic conditioning factors are internal or external and affect an individual's ability to engage in self-care (Hurst *et al.*, 2005; Lee, 1999; Slusher, 1999). Only two studies utilizing Orem's theory explicitly addressed basic conditioning factors in the analysis of data (Denyes, 1988; Hurst *et al.*, 2005).

Two studies addressed self-care and self-care behaviors in rural midlife women (Buehler *et al.*, 1998; Williams and Schreier, 2004). Buehler *et al.* (1998) identified self-care as a step taken by rural women in the symptom-action-time-line process (SATL) of responding to actual or potential health problems. Williams and Schreier (2004) studied the effectiveness of informational audiotapes on self-care behaviors in rural midlife women with breast cancer. Distance was identified as a potential for compromised health care (Henson *et al.*, 1998).

2.1 Gaps in the literature

No studies were identified related to the relationship of self-care to rural mid-life women and obesity. No studies utilized both Orem's theory and the rural nursing theory as a theoretical framework. In the studies reviewed, the need to identify BCFs and the need to explicitly address BCFs in the analysis was identified. Limited studies explored health-deviation self-care requisites and self-care agency power components. The impact of the rural environment on self-care and obesity in rural midlife women is an area lacking research.

3 RESEARCH METHODOLOGY

The relationship between self-care agency, self-care, and obesity in rural midlife women was studied utilizing a non experimental, predictive correlational design.

3.1 Instruments

Participants completed three instruments (Demographic Instrument, Denyes Self-Care Agency Instrument (DSCAI-90©), and Denyes Self-Care Practices Instrument (DSCPI-90©). Anthropometric measurements were height and weight. Body mass index (BMI) was calculated. Permission was obtained for the copyrighted instruments.

The Demographic data instrument addressed select BCFs. The BCFs for the study were organized by sets as recommended by Orem literature (Hurst *et al.*, 2005; Orem, 2001). Set one included age, marital status, ethnicity, number of children living in the home, and education. Set two, pattern of living, included tobacco use and place of residence. Set three, health state and health system, included health state, date of last physical exam, number of chronic conditions, insurance, and distance from health resources. The demographic data instrument included five open-ended questions related to health, self-care, impact of distance, facilitators and barriers to self-care. A pilot study to assess face validity was conducted with five members of the public not associated with the research project.

Denyes Self-Care Agency Instrument (DSCAI-90©) measures self-care agency. The instrument was originally designed for use with adolescent populations, but has been utilized effectively in adult populations (Anderson, 2001; Baker, 1997; Campbell, 1989; Campbell and Soeken, 1999; Campbell and Weber, 2000; Hurst *et al.*, 2005; Lee, 1999). The DSCAI-90© is a 34 item self-report instrument. The ratio scale yields scores from 0 to 100. A visual scale is available to aid participants. A total score and six scale scores can be calculated. The six scale scores are ego strength, valuing of health, health knowledge and decision-making capability, energy, feelings, and attention to health (Denyes, 1990).

Content and construct validity were established by factor analysis, pilot testing, and correlation between self-care agency, self-care practices and health status (Campbell and Soeken, 1999; Canty-Mitchell, 2001; Denyes, 1988; Hurst *et al.*, 2005; McBride, 1991). The factor analysis and correlation of the instrument with self-care practices to determine construct validity was established using 181 adolescents (Canty-Mitchell, 2001; Gast *et al.*, 1989). Evidence of internal consistency, test-retest and alternate forms of reliability were demonstrated in the initial instrument development (Denyes, 1988). Cronbach's alpha coefficient has ranged from 0.87 to 0.92 in previous research (Anderson, 2001; Baker, 1997; Campbell, 1989; Campbell & Stoken, 1999; Canty-Mitchell, 2001; Denyes, 1988).

Denyes Self-Care Practice Instrument (DSCPI-90©) is a general measure of self-care or self-care activities that meet universal self-care requisites (Andrews *et al.*, 2009; Denyes, 1988; Slusher, 1999). The instrument is appropriate for use with healthy populations as well as diseases/conditions (Andrews *et al.*, 2009). The instrument was based on Orem's definition and theory of self-care (Andrews *et al.*, 2009; Denyes, 1988; Gast *et al.*, 1989). The DSCPI-90© is a self-report 18-item. The ratio scale yields scores from 0 to 100. A visual scale is available to aid participants (Denyes, 1990). The original instrument development research demonstrated internal consistency, test-retest reliability, content, and construct validity (Denyes, 1988; Frey and Denyes, 1989). Construct validity has been supported by correlation between DSCPI scores and self-care agency and health status (Anderson, 2001; Dashiff, McCaleb, and Cull, 2006).

Andrews, Richard and Aroian (2009) conducted a factor analysis and concurrent validity of a measure of self-care. The population was 308 registered nurses in a large south eastern hospital system. Findings identified that the 18-items were normally distributed. Alpha coefficient for the total scale was 0.92. The analysis supports that the instrument is multidimensional. The factor analysis conducted was the first published analysis of the instrument since 1988 (Andrews *et al.*, 2009).

3.2 Setting and Sample Population

The study setting was ten counties in the northeast portion of South Dakota. South Dakota is located the north-central part of the United States.

The sample was a convenience sample of women, ages 40-64 years, ambulatory and able to read and write English. Marital status was neither exclusion nor inclusion criteria. Excluded from the study were women living in an assisted living, nursing home, or receiving home health care services.

3.3 Human Subjects Approval

Approval for this study was obtained from the South Dakota State University's Human Subjects Committee. Participants received information about the risks and benefits, nature of their involvement, and the purpose of the study. A cover letter contained an implied consent statement. Confidentiality of the participant's identity was maintained by the removal of names and any identifiers.

3.4 Subject Recruitment

Recruitment included notices in the local newspapers, flyers in community centers, grocery stores, convenience stores, health care facilities, and a county fair booth. As a recruitment incentive, all participants were eligible for a $20 gift card drawing at the conclusion of each data collection session.

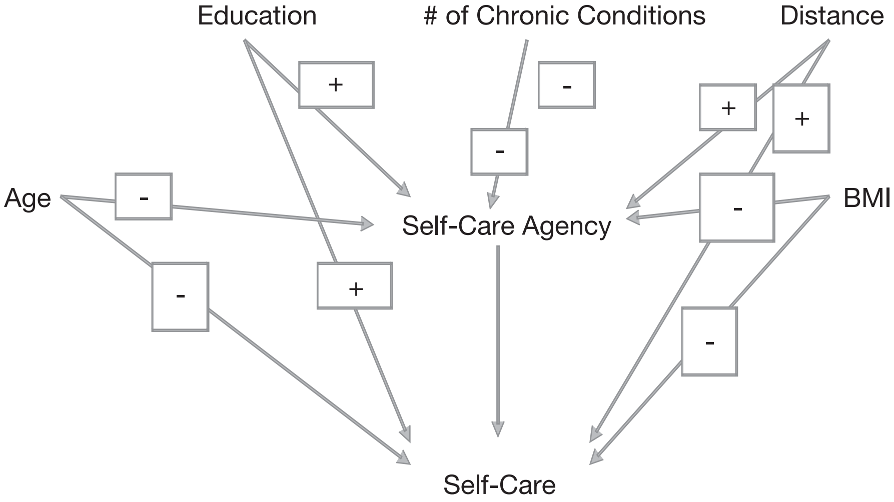
3.5 Data Collection, Entry, and Analysis

A standardized process was followed for each data collection session. Data were stored in a locked file cabinet. Demographic data and measurement/instrument data were stored separately.The PASW® Statistics Grad Pack 17.0 was used to analyse the quantitative data. Frequencies were compiled on the BCFs, instrument scores, and BMI. Pearson's Product-Moment correlation coefficient (r) was utilized to quantify the relationship between total score of SCA, SCP and BMI, and BCFs. Multiple regression was used to predict outcomes and explain interrelationships among variables. Path analysis was utilized to test the relationship between the independent and dependent variables. Both direct and indirect effects were studied.

Based on critical literature review and study research questions, a path model was designed (Figure 2). The path analysis was used to test the correlational relationship among education, age, number of chronic conditions, distance from healthcare provider, body mass index (BMI), self-care agency and self-care.

Data from the open-ended questions were analyzed for clusters of similar ideas until no new ideas emerged. The clustered ideas are identified themes. The goal of the data analysis was to illuminate the experience of rural midlife women.

Figure 2. Theorized model of self-care in rural mid-life women.



4 FINDINGS AND DISCUSSION

The convenience sample was 224 women. Ethnicity was 98.7% White with 0.4% American Indian and 0.4% Asian. The average age was 52.15 years of age (*SD*=5.932) with 81.3% married. Participants employed full-time were 80.8%. Bachelor degree was identified most frequently as the highest education level (*n*=65, 29.1%).

The average number of children high school or younger living at home was 0.60 (*SD*=0.951) with 63.8% (*n*=143) having no children living at home. The range was from zero to five children.

The majority of participants identified their health status as very good (44.6%) or good (36.6%) with the mean score of 3.56 (*SD* = .801) on a scale of 1(poor) to 5(excellent). Participants averaged 0.8 chronic diseases with a mean time from last physical exam of 9.5 months. Hypertension was the most reported chronic disease (27.8%).

The mean body mass index for the participants was 29.165 (*SD*=6.969, *n*=224). The mean height was 64.501 inches (*SD*=2.621). Mean weight was 172.04 pounds (*SD*=41.54). Overweight and obese participants accounted for 68.4% with 35.8% of participants in the obese BMI category.

Table 1. BMI Classification in Rural Midlife Women (*n*= 224)

BMI Classification	Obesity Class	Frequency	Percent
Underweight (<18.5)		1	0.4%
Normal (18.5-24.9)		70	31.3%
Overweight (25.0-29.9)		73	32.6%
Obesity (30.0-34.9)	I	38	17.0%
(35-39.9)	II	23	10.3%
Extreme Obesity (>40)	III	19	8.5%

The mean for DSCAI-90© was 75.713 (*SD*=10.06). The mean scores of each of the 34 items of the DSCAI-90© ranged from 37.871 to 94.804. Cronbach's alpha for this tool was 0.809. The mean for DSCPI-90© was 65.814 (*SD*=16.657). The mean scores of the each of the 18 items ranged from 53.237 to 85.371. Cronbach's alpha for this tool was 0.917.

4.1 What are the major facilitators and barriers to self-care agency in rural midlife women?

Facilitators to SCA were education (*r*=.213, *p*=.001) and health status (*r*=.455, *p*=.000). Education as a facilitator for SCA is consistent with previous research (Campbell and Soeker, 1999; Campbell and Weber, 2000; Lee, 1999). There is a statistically significant positive relationship between SCA and SCP (*r*=.693, *p*=.000) indicating participants with a higher self-care agency score had higher self-care practices.

Smoking was a barrier to SCA with a statistically negative relationship with smoking currently or in the past (*r*=-.135, *p*=.043). The findings indicate that smokers either past or current have lower SCA. No significant correlation was found between chronic disease and SCA.

The facilitators, barriers, and self-care practices through hierarchical multiple regression explained 50% of variance of self-care agency (Table 2). Data was reviewed for multicollinearity with tolerance (.699-.973) and variance inflation factor (VIF) (1.021-1.42).

Qualitative themes identified as facilitators to SCA by the study participants were knowledge, importance of health, and positive reinforcement by family and friends. Two questions on DSCAI-90© ask percent of time family and friends encourage you to take care of your health. The mean responses to the questions were 37.871 and 44.121 respectively. This finding indicates that positive reinforcement by family and friends is seen as a facilitator but may not be occurring on a consistent basis.

Themes identified as barriers to SCA were balancing personal, family and work needs; lack of energy; and lack of motivation and self-discipline. One participant wrote, "I have so many commitments with family, work, church and activities that I don't have time". Another participant wrote about the energy needed to work in town.

Table 2. Hierarchical Regression Analysis of Facilitators and Barriers on SCA

Step	*β*	R^2	R^2 Change	Significance	
Step 1		.226	.226	*F* (2, 219) = 31.917, p=.000**	
Health Status	.431**				
Education	.142*				
Step 2		.230	.005	*F* (3, 218) = 21.735, p=.000**	
Health Status	.421**				
Education	.142*				
Smoking	-.068				
Step 3		.501	.270	*F* (4, 217) =54.373, p=.000**	
Health Status	.100				
Education	.109*				
Smoking	-.009				
SCP	.622**				

**p<0.05. Dependent variable: SCA. β= Standardized regression coefficients. n=224

4.2 What are the major facilitators and barriers to self-care practices in rural midlife women?

Education (*r*=.139, *p*=.038) and employment (*r*=.132, *p*=.049) were identified as facilitators to SCP. This finding is support by previous studies (Lee, 1999, Campbell and Soeker, 1999; Campbell and Weber, 2000). Hurst *et al.* (2005) found no significant correlation between education level and SCP. Health status (*r* =.538, *p*=.000) was found to be a facilitator to SCP. Previous studies have identified SCP as a promoter or predictor of health state (Anderson, 2001; Campbell and Soeker, 1999; Denyes 1988; Frey and Denyes, 1989; Lee, 199).

Barriers to SCP were smoking (*r*=-.171, *p*=.011) and chronic illness (*r*=-.194, *p*=.004). Denyes (1988) found presence or absence of health problems not significantly correlated with self-care practices.

The facilitators, barriers, and self-care agency through hierarchical regression explained 56% of the variance of self-care practices or the concept, self-care(Table 3). No problems with multicollinearity were identified from tolerance (.769-.993) and VIF (1.007-1.365).

Qualitative themes identified as facilitators to SCP were family and friends; knowledge; use of the internet; and group support. A participant indicated that a facilitator was "having family and friends". Participants identified acquiring knowledge from health magazines, healthcare provider, books, internet and printed materials, and television. Participants report use of the internet to acquire information on self-care and maintain health. Participants identified group exercise class or group challenges as a facilitator of self-care.

Barriers identified by participants were: time, motivation and self-discipline, and money. One participant stated "finding/making time to be every place/ placing priorities at home. Not enough hours in the day for self". One participant commented 'mostly lack of self-discipline when making healthy choices. It is difficult to turn down a good German meal". A participant commented, "Finances, foods that are good for you are more expensive in the winter". The rural culture was identified as a barrier to self-care. A participant wrote "how I was raised in a rural community".

Table 3. Hierarchical Regression Analysis of Facilitators and Barriers on Self-care Practices

Step	β	R^2	R^2 Change	Significance
Step 1		.304	.304	*F*(3, 217) = 31.555, p=.000**
Education	.052			
Employment	.093			
Health Status	.431**			
Step 2		.314	.011	*F*(5, 215) = 19.715, p=.000**
Education	.057			
Employment	.091			
Health Status	.497**			
Smoking	-.085			
Chronic	-.058			
Step 3		.559	.245	*F*(6, 214) =45.273, p =.000**
Education	-.023			
Employment	.086			
Health Status	.258**			
Smoking	-.047			
Chronic	-.064			
Self-care	.564**			

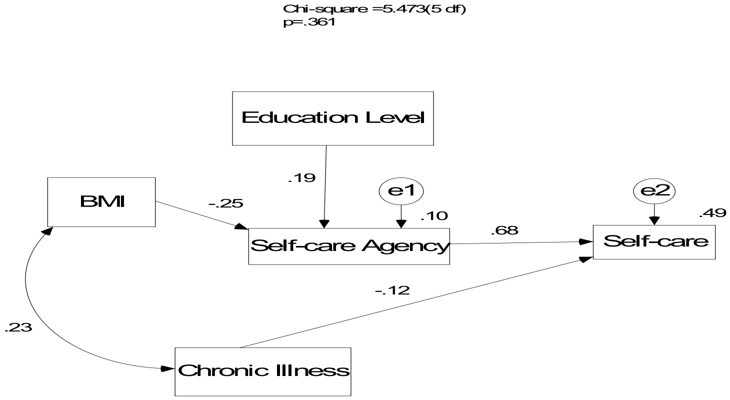
***$p<0.05$. Dependent variable: SCP. β= Standardized regression coefficients. n=224*

4.3 What is the correlation between basic conditions, BMI, self-care agency, and self-care practices in rural midlife women?

Path analysis was conducted on the hypothesized model. The hypothesized model suggested a positive direct path between education, distance and the two dependent variables (SCA and SCP) with a negative direct path between age, BMI, number of chronic diseases. After two revisions, the final model was identified.

The Final Model was constructed with the independent variables, education level, BMI, and number of chronic diseases (Figure 3). The dependent variables remained SCA and self-care (SCP). All paths in the final model were significant at the 0.01 and 0.001 levels. Good of fit indices (NFI, CFI, and RSMEA) indicate a good fit for the final model. The final model suggests that as BMI increases the level of self-care agency decreases leading to a decrease in self-care. Conversely, as the level of education increases the level of self-care agency increases leading to increased self-care. When the number of chronic diseases increases, there is a decrease in self-care.

Figure 3. Final Model, Self- care in Rural Midlife Women with Standardized Coefficients (β).



4.4 A negative relationship exists between self-care agency and BMI in rural midlife women.

The hypothesis was supported by the findings. A statistically significant negative relationship at the 0.01 level was identified between BMI and self-care agency (r=-.266, p=.000, n=223, r^2=.07).

Simple linear regression was conducted to develop a prediction equation, SCA=86.91-0.384 BMI, (F (1,221)=16.887, p=.000, β=-.384, 95%CI [81.388, 92.428]). F-test for slope confirmed BMI may be used to predict self-care agency (F_{crit}=6.67).

4.5 A negative relationship exists between self-care practices and BMI in rural midlife women.

The hypothesis was supported by the findings. A statistically significant negative relationship at the 0.01 level was identified between BMI and SCP (r=-.278, p=.000, n=224, r^2=.077). Simple linear regression was conducted to develop a prediction equation, SCP=85.209-0.665 BMI, (F (1, 222)=18.628, p=.000, β=-.278, 95%CI [76.105, 94.313]). F-test for slope confirmed BMI may be used to predict self-care (F_{crit}=6.67).

4.6A positive relationship exists between self-care agency, self-care practices and the distance from healthcare provider in rural midlife women.

The hypothesis was not supported. No statistically significant positive relationship was noted between the total SCA score (r=-.009, p=.445, n = 219), SCP (r =.017, p =.148, n= 219) and distance to healthcare provider. Participants (90.5%, n =190) reported no impact of distance on access to healthcare.

4.7 Meaning of Self-care

Orem defined self-care as "practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being" (Orem, 2001, 43). Rural nursing theory identified self-care as "activities self-initiated and performed for self or family members in response to symptoms" (Buehler *et al.*, 1998, 322). Participants were asked to respond to an open-ended question, "What does self-care mean to you?" The written qualitative data was analysed for cluster/themes until no new ideas emerged. The definition derived from the data was: self-care is taking care of and responsibility for self by making good choices and remaining independent. This definition is congruent with Orem's definition. However, the definition is not congruent with rural nursing theory concept of self-care.

4.8 Meaning of health

Health, as defined by Orem, is a state of being whole and sound (Morales-Mann and Jiang, 1993). Rural nursing theory defines health as being able to do what the person wants to do; it is a way of life and a state of mind (Lee and McDonagh, 2006). Participants were asked to define health. The written qualitative data was analysed for cluster/themes until no new ideas emerged. The definition of health derived from the data was: health is well being of mind, body and soul supporting the ability to work and play. The definition supports both Orem and Rural Nursing Theory definitions.

5 CONCLUSION AND FURTHER RESEARCH

The study identified facilitators, barriers to SCA and SCP. Findings confirmed that self-care agency is a predicator of self-care. This finding is consistent with previous research (Anderson, 2001; Baker and Denyes, 2008; Denyes, 1988; Lee, 1999; Slusher, 1999; Wang, 2001).

A causal model, self-care in rural midlife women, was hypothesized and tested. The strongest effect on self-care was SCA with BMI and education providing indirect effects. The strongest effect on SCA was the negative effect of BMI. Number of chronic illnesses also provided a negative effect on self-care. Level of education provided a positive effect on SCA.

The model suggests that interventions to increase SCA must address BMI. Interventions to increase self-care should focus on the effects of any chronic disease and increasing SCA. Interventions should be tailored to address BMI and education levels.

BMI were found to negatively influence SCA and SCP. The number of chronic diseases did not negatively influence SCA, but did influence SCP. Distance did not negatively affect the participants' ability to care for self.

Self-care was defined as taking care of and reasonability for self by making good choices and remaining independent. This definition is congruent with Orem's definition. However, the definition is not congruent with rural nursing theory concept of self-care.

Health was defined as well being of mind, body and soul supporting the ability to work and play. The definition derived from the study supports both Orem and rural nursing theory definitions.

5.1 Nursing Practice Implications

Through understanding the relationship of obesity, self-care agency and self-care practices, nursing may address the obesity epidemic. The meaning of health and self-care for rural midlife women can assist nursing in the identification of strategies to promote health and self-care. The facilitators and barriers identified provide nurses with knowledge for designing strategies to promote SCA and SCP.

5.2 Nursing Education Implications

The addition of the rural nursing theory is suggested for all levels of nursing education in rural areas. Nursing education should provide opportunities for students to develop and tailor interventions to promote health, self-care and self-care practices for rural residents.

5.3 Strengths of the study

The study is grounded in a nursing theoretical framework. The study utilized Orem's self-care and rural nursing theory. The study is the first to link self-care agency, self-care and obesity with rural mid-life women. The study provided definitions for health and self-care from a rural midlife woman's perspective.

5.4 Limitations

The study was conducted during the summer months. Self-care behaviors may vary with seasons and not be representative. The self-report of chronic disease has a potential for underestimation of chronic diseases. The study lacked ethnic diversity. The study was conducted in a portion of the state and not be representative of the entire population. The findings are only representative of the study population and are not to be generalized. The path analysis does not confirm causation, but is a diagram of the patterns of correlation and may reflect a hypothesis of causation.

5.5 Recommendations for future study

Additional research is needed to understand the relationship of the rural environment and the health of midlife women. A longitudinal study should be conducted to determine changes in SCA and SCP over time and seasons. DSCAI-90© and DSCPI-90© instruments should be tested further with rural and Native American cultures to identify validity and reliability with these cultural groups. Further research is suggested to test the final model, self-care in rural midlife women, with other populations and ethnic groups. Research is needed to test interventions that target the barriers and facilitators of self-care agency and self-care to decrease BMI in rural midlife women. The underlying mechanism of the relationship between self-care agency, self-care, and BMI in rural midlife women remains unclear and further research is needed to define the relationship.

The relationship of distance to healthcare provider, SCA and SCP warrants further study with frontier and other rural populations. Research on the impact of technology on the concept of distance would assist with tailoring interventions.

5.6 Conclusion

The prevalence, economic and health consequences of obese and overweight identified substantial needs to be addressed at the personal, local, national, and global levels. Nursing as a profession must be an active player in identifying solutions for the obesity and overweight crisis. Increasing nursing knowledge of the relationship of self-care and obesity among mid-life women in the context of the rural environment can provide new knowledge to address the obesity crisis.

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CHALLENGING RN-BSN STUDENTS TO APPLY OREM'S THEORY TO PRACTICE

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ABSTRACT

It is a challenge to engage RN-BSN students in learning to apply nursing theory. In associate degree nursing programs, nursing theory is barely mentioned and not discussed in detail. This paper reports the experience of one university nursing program that adopted Dorothea Orem's nursing theory as the basis for its curriculum. The RNs were introduced to Orem's theory in their first course. Subsequent courses continued to build on this knowledge.

An issue of importance to professional nursing was chosen by the professor for the Nursing Issues course, in their 3rd sequence of classes. In an attempt to engage RN students in applying Orem's theory, a group project was designed to help them apply the theory to their practice. Groups of four were assigned a "characteristic" of nursing agency. Because this was a hybrid course, much of the group work occurred online, with both student and professor posting articles from the literature. Formative evaluation was given. In the last face-to-face class, the groups presented, and students were able to see a holistic view of an issue of importance to nursing, with Orem's theory providing context. By applying Orem's theory to a nursing professional issue, the RNs learn the theory and its relevance to their current practice.

KEYWORDS

nursing agency, nurse characteristics, Orem, RN-BSN education

1 INTRODUCTION

The American Nurses Association (ANA) established the bachelor of science in nursing (BSN) as the minimum degree requirement for professional nursing (ANA, 1965a). At that time, many nursing programs were located at community colleges and awarded the two year associates degree while colleges and universities offered the four year BSN degree. The availability of nurses has gone through periods of surplus and shortage, but the current conditions point to a much greater problem. Goodin (2003) demonstrated that the aging of the nursing workforce is happening on top of a period of shortage. The effect is that the size of the total workforce is not keeping pace with both current demand and replacement of retiring nurses. Further, more medical settings are requiring the BSN as the entry degree as they attempt to reach Magnet Recognition by the American Nurses Credentialing Center (ANCC, 2011). Nurses currently working with an Associate's degree or diploma certificate, are often encouraged to complete the BSN as part of their continuing professional growth. The result has been a tremendous push to increase the number of non-degree nurses who complete the BSN (National Advisory Council on Nurse Education and Practice, 2006). Baccalaureate nurses have been shown to provide better patient care (Aiken, Clarke, Sloane, Lake, & Cheney, 2008), and the professional standing of nurses is supported. As a result, associate degree registered nurses (RNs) are returning to the classroom in record numbers to obtain the BSN degree. The reason for this return for further nursing education has many explanations. The BSN may be required for job promotion, a requirement for employment, the next step in pursuit of a graduate degree in nursing, or personal satisfaction. The healthcare facility where the RNs are employed may be seeking Magnet Recognition status which requires a high percentage of RNs to have the BSN degree (ANCC, 2011).

Whatever the motivation, pursuing further nursing education is a challenge. Most RNs are working full time jobs as well as dealing with family and personal responsibilities. Education is in addition to an already busy life; for many, it has been a number of years since they were in a classroom.

Associate degree programs do not include a separate course in nursing theory as with BSN programs, so students typically enter the BSN program with little or no knowledge of nursing theory. Those who have heard of nursing theory are suspicious of its usefulness. A number of BSN programs organize their curriculum around a particular nurse theorist. Nursing theory and theorists have a unique vocabulary. This can be confusing initially to RN students who have been educated and practice using a medical model. The challenge for the nurse educator is to create a learning environment where the RN student not only learns nursing theory and its language, but incorporates it into practice.

The faculty in a baccalaureate program designed an RN-BSN curriculum based on the theory of Dorothea Orem (2001). The traditional BSN program in the School of Nursing had already organized its curriculum using Orem's Self Care Deficit Theory of Nursing. The nine courses in the RN-BSN program incorporate Orem's theory. This paper will look at one particular course, the nursing issues course, to demonstrate how Orem's theory was applied to current practice issues.

2 THE NURSING ISSUES COURSE

With the large enrollment in the class, (30-50), group projects are one way to maximize the class time and involve all of the students in the learning process. To decrease the stress on the students, the course professor designed a class group project allowing each group to come up with individual ideas to present based on a characteristic of nursing agency.

Nursing Issues, the target course, is taught in a hybrid format over 7 weeks with three face to face class meetings. Since all students in the class were involved in full time employment, the project had to be based on a relevant nursing issue that would engage, challenge and interest the students (Davidson, Metzger & Lindgren, 2011). The students were divided into groups. Each group was labeled according to one of the designated nursing agency characteristics from Orem's theory. This was done in an effort to help the RN students become familiar with Orem vocabulary and begin to incorporate it into their practices.

3 THE GROUP PROJECT

Nursing agency encompasses the skills and life experiences a nurse gains over the years through education and practice. According to Orem (2001), there are three domains of nursing practice for which she describes desirable characteristics. From Orem's description, the faculty identified specific desirable characteristics of nursing agency relating to the social, interpersonal, as well as professional technologic role of the nurse. The student groups were assigned each to one of the following desirable characteristics: effective repertoire of communication skills; transformative teaching; leadership; ethical practice; prudent (legal) practice; cultural sensitivity; and professional behavior (Secrest, 2010). The instructions for the group project were outlined as follows.

1. Working within the context of your group, research the issue named. Use the group discussion board, the weekly discussion questions, your individual searches as well as group findings to address the issue.
2. Develop a nursing department in-service on how you would implement the project from your group's viewpoint. Look at the

> characteristics of nurse agency and the project topic to develop your in-service. Remember, this is a whole new way of thinking or approach for some nurses. Your group is in charge of this in-service to educate the nursing staff. This is your paper and power point presentation.

During the 7 week course, discussion questions were posted weekly pertaining to the group topic. Also, articles of interest were posted along with the charge for the students to find related articles. The discussion questions centered on the students' perception of the group project in relation to the nursing agency characteristic. For example, over the past four years that the course has been taught to RN students, the following topics have been addressed: Obtaining Magnet Recognition, Mandatory Nurse to Patient Staffing Ratios, Nurse Recruitment and Retention and Mandatory Continuing Education Units (CEU) to maintain nurse licensure.

4 THE ASSIGNMENT

The assignment involves research on the topic using current literature, develop a nursing staff in-service, submit a formal paper, and create a power point presentation. The last class is devoted to the presentations of aspects of a topic, pulling together a much broader perspective for all.

An example from a recent class went as follows: Many states require and many professional nursing organizations recommend continuing education units (CEUs) as an indicator of competency in the profession and to maintain licensure. Should registered nurses in the state of Tennessee be required to complete CEUs to maintain licensure and competency? If so, how might this requirement be structured? How many CEUs are sufficient to maintain competency and licensure? Is obtaining CEUs a true measure of competency? If you do not think CEUs should be required, why not? Do you propose some other method for registered nurses to maintain competency and licensure? How does Orem's theory address continuing education?

Each group began by defining its nursing agency characteristic. Next, group members researched what the state of Tennessee requires for RN nurse competency and maintenance of licensure. An exploration of what other states required was conducted. The groups also reviewed the requirements at the facility in which they practiced. Finally, the groups researched what professional nursing organizations recommended, to begin their discussion.

The weekly discussion boards and assignments helped the students to focus on the group project. The first week started with having them discuss how nursing as a profession has contributed to the improvement of healthcare in the U.S. This was to be based on what they had read from posted articles as well as articles they searched for and posted for their group. They were asked to identify the laws, regulations and standards under which they practice as a registered nurse. In addition, did the facility where they currently practice support and use these laws, regulations and standards of practice? What factors determined their decision to work at their current facility? Was the environment one that supported professional nursing behavior? Does practicing at a health care facility that incorporates a nursing theory enhance the professional environment? The weekly reflection papers centered on addressing the questions posed from the nursing agency characteristic of their group.

Each group first had to decide its position on mandatory CEUs. If they responded yes, they had to structure a program on how many CEUS' would be required, what topics would be covered, and how the CEU's would be offered to the nursing staff. Several groups suggested five CEU's per year to cover the following five topics: prevention of medication errors; legal documentation; pain management; ethical issues; and workplace violence. This group located these topics as CEU offerings on the state board website. The topics are free and a certification of completion can be printed out. The requirement would be annually.

5 CHARACTERISTICS OF NURSING AGENCY

The group with the nursing agency characteristic of *effective repertoire of communication skills* looked at how to inform the nursing staff of CEU requirements to maintain competency. This group looked at Orem's definition of communication as follows: "To make common among humans intangible things such as thoughts, feelings, or information expressed in some tangible way as through statements or diagrams" (Orem, 2001, p. 515). They took this definition and looked at the following ways to communicate with the nursing staff. Examples mentioned were informational staff meetings, online information in facility newsletters, posters, email notification and *potty post-its*. The *potty post-its* is a creative way that involves posting flyers on the inside stall doors of the bathroom. This group proposed that a variety of communication methods would need to be implemented to ensure that all nursing staff was aware of the requirements and how to obtain them.

The *prudent (legal) practice* group applied Orem's theory to support continuing education as necessary to assist the patients to meet self-care requisites. Nursing care is needed when patients are unable to meet self-care requisites. When a patient has a self-care deficit, nursing care and education are needed in order to regain a state of normalcy. Orem (2001) stated "The nurse attends to his or her legally and occupationally defined roles and responsibilities…." (38) and poses the question, "Am I legally and occupationally qualified to take on the roles and responsibilities of nurse in this practice situation?" A patient care example used by the group involved a patient presenting to the emergency department in an active tonic-clonic seizure. Usual practice in the community a few years ago would have been to place a bite block in the patient's mouth. Research and evidence based practice have shown that it is not prudent to insert a bite block when a patient is seizing for fear of causing damage to the patients teeth and jaw. This group concluded that in order to help the patient reach full self-care agency, a nurse must be competent and up-to-date on current nursing care to include wholly compensatory, partially compensatory or supportive-educative care.

The *transformative teaching* group viewed its charge as follows: "to use teaching as a method of assisting others, it requires that the helper know thoroughly what the person to be helped needs to know" (Orem, 2001, 59). This group decided to distribute a survey tool to the nursing staff for input as to what the staff thought were the topics that needed to be required each year. This involved topics pertinent to all nurses. The nurses would then choose two topics for their specialty area of practice. This group wanted to capture the nurses' interest by getting their input and then offering the topics the nurses thought necessary to maintain competency.

The *professional behavior* group suggested annual renewal by completing five CEU's in the following manner: five CEU's per year for the nurse who has worked 1,600 hours or more; ten CEU's per year for the nurse who has worked 1,000 to 1,599 hours; and 15 CEU's per year for the nurse who has worked 200 to 999 hours. For those nurses who have worked less than 200 hours per year, the requirement would be 15 CEU's and 20 hours volunteer work in a medical setting using nursing knowledge and skills in performing patient care. This group then listed a number of professional nursing organization websites that offer CEU's. They saw professional behavior as "the ability of nurses to creatively design adequate means for identifying and describing nursing requirements and to design, put into operation, and manage systems of nursing assistance for individuals, families and groups is one characteristic of the professional nurse" (Orem, 2001, 93).

The *leadership* group included the nurse managers and nurse leaders as well as nursing staff who needed to be compliant with maintaining competency in nursing practice. This group looked at the technologic domain of nursing agency characteristics and concluded that according to Orem (2001), the technologic domain addresses leadership as follows, "Is able to integrate the use of methods of helping with the technologic operations toward the production and management of effective nursing systems for individuals and multi-person units" (292). This group went on to say that nurses should be involved in lifelong learning to keep up with the ever changing environment in healthcare. They also concluded that managers and leaders should be held to a higher standard of annual competency. As leaders, they are role models to the nursing staff and should not just mandate what needs to be done, but be examples also. See Table 1 for summary.

6 SUMMARY

Nursing agency and its various characteristics are "a set of developed and developing capabilities that persons who are nurses exercise in the provision of nursing for individuals or groups" (Orem 2001, 289). In this course, the groups are other nurses who have a need for education on a particular topic. The need requires interaction by nurses with other nurses. As a result of this course and this group project, the RN students gained a better understanding of how to base their practice in theory. This course format has been very highly rated by students. Some of their comments include:

> "*The group discussion and project was a different approach to learning and applying a nursing theory in real life.*"
>
> "*This class has really broadened my knowledge on Dorothea Orem and heightened my curiosity so that I will do further research on her theory.*"
>
> "*I have a better perspective of what nursing really is after learning to apply Orem's eory to my practice.*"
>
> "*By taking this class, I gained a better understanding of how nursing fits into the healthcare field.*"
>
> "*This is the first class I have ever had in which I was able to learn in whatever way was best for me at the time, and with the general subject matter augmenting the primary framework (Orem) provided by the course.*"
>
> "*That I actually use nursing theory in my practice every day!*"

As many of the students are not enthusiastic about learning nursing theory when they enter the program, these comments have been very gratifying. The RNs not only learned about Orem's theory but realized that nursing theory plays an important role in their practice.

Conclusion

The application of a theory to nursing practice provides many distinct advantages. First, by providing organizing principles to evaluate patient care, the nurse has a rationale for making decisions. Second, as nurses encounter the rationale for patient care, it encourages them to ask more broadly about the theory or evidence that supports practice. From these two advantages we also compliment training on how to systematically evaluate, set guidelines, and apply abstract principles, all of which encourage critical thinking. Finally, nurses regularly report a reconceptualization of their role as a nurse. By using Orem's theory in the curriculum, RN students now see their profession as having an intellectual basis. When they view their practice through the application of theory, it opens them to more self-reflection for professional development.

Table 1. Example of course topic with student group examples for the characteristics of nursing agency.

Characteristics	Examples of Focus
Effective Repertoire of Communication	Staff meetings, newletters, posters, email and potty post-its
Prudent Legal Practice	Standards of care, evidence based practice
Professional Behavior	Managing systems of nursing
Leadership	Life long learning, leaders & managers as role models
Transformative Teaching	What does the RN need to know?

Topic: Continuing Education Units for Continued Competency Requirements for Licensure

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THE NUTRITION SELF CARE INVENTORY

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ABSTRACT

The purpose of this planned study is to develop and evaluate The Nutrition Self Care Inventory (NSCI). The NSCI is a pilot tool designed to assist the advanced practice nurse in the development of nurse and patient co created individualized meal plans for clients who are obese and overweight.

Obesity and overweight are the precursors to metabolic syndrome, diabetes and cardiovascular disease. Metabolic syndrome is a constellation of risk factors including: obesity, elevated cholesterol, elevated blood pressure, elevated blood sugar and/or increased waist circumference and can be considered the precursors to these diseases. Obesity is a national and global concern.

The Self-Care Deficit Nursing Theory frames this study. Orem's theory illustrates the person's need to identify with normal human behavior and desires. Normalcy is a central theme of the theory (Orem, 2001).Young and middle age adults often desire to lose weight. To be overweight is considered to be in the outside parameters of normalcy, while overweight is found in the majority of adults in the United States. The strong influence of social dependency and the need to establish interpersonal relationships can affect an individual's behavior while searching for this normalcy.

Theoretical constructs will be measured by the use of a tool, designed to be used in a measurement model. In the development of this tool, the use of a concept tree (Tappen, 2011) allowed for the organization of thoughts and principals for mapping using Orem's Theory of Self Care Deficit Nursing concepts.

KEYWORDS

concept tree, nutrition, obesity, self-care deficit nursing theory, self-care tool.

1 INTRODUCTION

A concept tree was created to provide the theoretical basis for the development of a tool to establish the perceived nutritional status of participants diagnosed with obesity and overweight. This paper is important to the practices and theory of self-care deficit nursing and its further development of health specific tools. Construction of this tool will aid the advanced practice nurse in the plan and creation of the individual's weight loss goals.

2 THEORETICAL FRAMEWORK

Theoretical constructs can be measured by the use of a tool, designed to be used in a measurement model. The use of a concept tree (Tappen, 2011) allowed for the organization of thoughts and principals for mapping using Orem's Theory of Self Care Deficit Nursing (Figure1) A concept tree is a heuristic, a guide to thinking about and articulating the theoretical foundation using a tree diagram for clarity.

Concepts

Orem's theory illustrates the person's need to identify with *normal* human behavior and desires; Normalcy is a central theme of the theory (Orem, 2001).

Young and middle age adults often desire to lose weight. To be overweight is considered to be in the outside parameters of normalcy, while overweight is found in the majority of adults in the United States (ADA, 2011). Prevention of adverse health events is basic to the construct of health care plans. The strong influence of social dependency and the need to establish interpersonal relationships can affect an individual's behavior while searching for this normalcy. It is considered easier to conform to the normal practices than to behave outside the normal.

Propositions

The desire to be normal often outweighs the practical application of one's actions. Decision making regarding food choices not only impacts the individual but also the persons with whom that individual has a relationship. The relationship one has in the family social unit is interdependent on the choices and outcomes discovered in the co created meal plan. The choices made for meal planning need to be acceptable to those involved, including family acceptance of the plan. Guidance and counseling from the nurse can support these decisions which will reflect the healthy behaviors needed for change (Hartweg and Fleck, 2010).

Dimensions

The individual coming for healthcare and counseling is part of the decision making for the healthcare plan. Obesity, metabolic syndrome, diabetes and heart disease are often the precursors to the healthcare appointment. The desire for change is established and the medication, food and activity plan is discussed. Food preferences and family cultures are entered into the construction, with emphasis on carbohydrate control and counting. This is done by the use of a food guide that allows choices for familiar and favorite foods to be counted. The ongoing relationship of the individual and the nurse will enhance the strength of the choices and identify the obstacles incurred as the barriers to the co created plan. Ongoing communication through the office visit will enhance evaluation of the desired outcome; weight loss.

3 METHODOLOGY

Tool Development

The use of a tool for information gathering is helpful to the advanced practice nurse. Time constraints and healthcare reimbursements often curtail the ideal situation for counseling. Quick and useful tools can be used to assist the nurse in assessment and planning at the healthcare appointment. Individualization of meal planning allows the person to enjoy their typical food choices while counting their budgeted carbohydrate intake. Individualized meal planning was studied by Fleck (2007). Participants were counseled regarding controlled carbohydrate meal planning in the quest to lose weight.

The Self-as-Carer Inventory (Geden and Taylor, 1991) was used to assist in the perceived self-care of these participants and the consideration of disease specific items (Table 1). Further research is considered to explore this counseling intervention after tool development for assessing *nutrition specific* information.

A review of current nutrition tools led to the discovery and lack of those published in the nursing literature. Paxton and Strycker, *et al.*, (2011) found a lack of valid measurements related to health behaviors in primary care. Dietary assessment tools are often found to be costly and burdensome for the evaluation of nutrition self behaviors. A simple dietary pattern tool was developed, *Starting the Conversation* (STC), as a means for cost effective and food group specific research focus (Table 2). This eight item tool distinctly measures different aspects of eating behavior. Item scores are added to create a summary score (range 0-16), with lower summary scores reflecting a more healthful diet. STC items were moderately intercorrelated. Individual items correlated significantly with the summary score (r=0.39-0.59, p<0.05). Overall the STC tool identified healthful and unhealthful dietary behaviors in a diverse sample.

Careful consideration of these previous tools and their significance in advanced nursing practice gave an impetus to the development of The Nutrition Self Care Inventory (NSCI) (Table 3). While reliable and valid tools are apparent for nutrition and perceived self-care practice, no tool was identified to measure both specific nutrition and perceived self-care practices. The NCSI was then developed to assist the advanced practice nurse with the gathering of information to assist in the co creation of a meal plan This co creation of food choices is essential to the weight loss plan.

The NSCI was designed to permit individuals to express their perceived capacity in nutrition decision making. The NCSI is a ten item likert type questionnaire. Since a general measure of nutrition self care is desired, the tool includes instructions for respondents to identify their perceived ability to make decisions regarding their nutrition practices. The scores range from 30 - 10 with higher scores indicating higher perceived nutrition self care; things they feel confident in their ability to do related to their nutrition practices.

4 RELIABILITY AND VALIDITY

Readability and clarity will be examined by administering the tool to 10 English speaking adults attending a family practice clinic. These adults will be identified by the use of ICD 9 codes to include obesity, hypertension, diabetes or metabolic syndrome.

Stability

Reliability will be concerned with consistency, repeatability, stability and homogeneity. Stability will be measured by comparison of one testing time to another testing time. Interater reliability is done by comparison of the ratings produced by two examiners at the same time with the same subjects. This will be implemented by two different raters with the same subjects one week apart. The coding is done by calculation of a score from 1-3 on each item of a 10 item questionnaire. Assumed stability of the phenomenon of nutrition self-care practice is considered. Pearson's correlation coefficient will be calculated.

Reliability

The practice effect, described above, often prevents researchers from accurate measures of the phenomenon. The practice effect considers a test of cognition or physical ability. In some instances the person actually practices what the researcher has asked them to do and performs better on the second testing (Tappen, 2011). The use of parallel forms of measure is not appropriate for this tool. A split half technique of comparing the first half of the measure to the second half of the measure can be used. The odd and even items would be compared. This measure is not chosen to evaluate this tool.

Cronbach's alpha will be calculated. It produces the correlations of individual items with a total score and estimates of the effect of removing an item (Tappen, 2011). Cronbach's alpha is a measure of internal consistency or homogeneity. A Cronbach's alpha score of .70 is acceptable for new measures.

Reliability of the NSCI will be studied using the test retest procedure. Administration of the NSCI will be given to a group of 100 English speaking adults. Consistency of responses will be compared on two separate measurement occasions under standard conditions (Waltz, 2010). The extent to which the two sets of scores are correlated at the interval level will be determined by the Pearson coefficient.

Content validity

Validity is defined as the degree to which evidence and theory support the interpretation for its intended purpose (Tappen, 2011). Face validity would reflect the areas that the items look appropriate. The items reflect nutrition issues and behaviors. Expert review will be carried out as well. Upon reanalysis by an expert panel (Family Nurse Practitioners) content validity will be established. The extent to which the items sampled for inclusion on the tool adequately represent the content and relevance of the desired information will be measured (Waltz, 2010). Three expert practitioners will rate the tool and an alpha coefficient will be employed as the index of content validity. Collection of data will provide evidence of the nutrition behaviors indicating the need for nursing. Gaps in the behavior of healthy food choices and practices can indicate the need for education.

Factor analysis can indicate a strategy of looking at individual items and their ability to measure in a cluster (Tappen, 2011). The basic sample size requirement is 5-10 cases per item to be factored. If the factors generated are congruent with the original theoretical mapping presented in the concept tree, they support the validity of the measure. The items might be subcatorized; behaviors in ability to calculate the carbohydrate counting, support and family dynamics in food choices and preparation and the financial ability to purchase food items. It is planned to have 100 participants for the needed factor analysis of 10 items.

Construct validity

Construct validity is concerned with how a measure relates to other measures (Tappen, 2010). Multitrait-multimethod (MTMM) is an extension of construct validity. It is a set of comparisons of data and measurement methods that are like (mono) the one being tested or unlike (hetero) the one being tested

(Tappen, 2011). A matrix will be designed to show the correlations generated by these comparisons.

Comparison measure of the information will be generated through traditional collection methods. The Advanced practice nurse will ask the usual intake questions and compare the self reported answers of the participant. Theoretical concepts of the two measures indicate the self reported information and the information generated by the nurse. Correlation of the two scales will give an indication of measure for similar concepts; nutrition self care (Tappen, 2011).

Criterion validity

The ability of the measure to predict the outcome of interest is called criterion validity. It is concerned with concurrent or predictive situations (Tappen, 2011). Scale predictions might be measured for choices. Meal planning is a choice and predictive choices will influence outcomes. Rice or green beans will have different outcomes on the glycemic index but may be very culturally influenced.

Sensitivity and specificity

How accurately a measure characterizes or diagnoses people is described by its sensitivity. Is the measure accurately reflecting the positive correlation of food choices and self care competence? Confirmatory factor analysis will be used to identify the construct validity.

5 CONCLUSION

The use of research tools to further develop and study nursing practice is imperative to the expanding base of nursing knowledge. Advanced practice nurses are the catalyst to change in healthcare practice that often requires less time and less money to accomplish more complex issues. Tool development in the areas of obesity, weight loss and metabolic disorders will serve this population of patients in cost effective individualized practice to obtain healthcare outcomes.

6 REFERENCES

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Attachment A

Figure 1. - Concept Tree

Grand Theory
Conceptual Framework
Orem
Self-Care Deficit Nursing Theory

Mid-Range Theory
Constructs

Theory of Nursing Systems
(therapeutic self care demands)

Motivation/Values Desire to be normal	Concepts Social dependency Family responsibilities cooking/shopping	Development of interpersonal relationships Family support/sharing of chores
Decision making for self cooking/shopping Life, health and well being Money/budget	Propositions Family acceptance of choices Ability to produce and manage Creation of meal plans	Relationships between nurse and person Initiating healthcare appointment
Diagnosis and prescription Desire to lose weight	Dimensions Design and plan Contribute to meal plan preferences Carbohydrate counting competence	Produce and control Maintain office appointments Identify obstacles

Attachment B

Table 1. - Self As Carer Inventory

Day of your birth/Last 4 digits of your social security number **Form B**

— — / — — — —
day soc. sec. #

Instructions: Below are a number of statements about caring for yourself. (The word "self-care" is used a lot. It means those things you do for yourself to maintain life, health, and well-being.)

Use a #2 pencil to mark the number that best describes how you take care of yourself. Marking the number "6" means the statement is a very accurate statement about how you care for yourself; marking number "1" means that the statement is not at all accurate.

	Very Inaccurate				**Very Accurate**	
1. My joints are flexible enough for me to take care of myself................................	1	2	3	4	5	6
2. I think about health information in choosing solutions to problems in caring for myself..	1	2	3	4	5	6
3. The way I take care of myself fits in well with my family life.............................	1	2	3	4	5	6
4. I try out new ways to take care of myself based on information from experts......	1	2	3	4	5	6
5. My self-care routine fits in with other parts of my life...	1	2	3	4	5	6
6. I watch for signs that tell me if I am taking good care of myself.........................	1	2	3	4	5	6
7. I use different ways of thinking based on the kind of self-care problem I have....	1	2	3	4	5	6
8. I watch for things around me that will make a difference in how I take care of myself..	1	2	3	4	5	6
9. I am strong enough for the physical work of caring for myself	1	2	3	4	5	6
10. I pay attention to signs telling me to change the way I care for myself	1	2	3	4	5	6
11. I plan my self-care by how much energy I have...	1	2	3	4	5	6
12. I am aware of things around me that affect how I take care of myself.................	1	2	3	4	5	6
13. I have the necessary skills to care for myself	1	2	3	4	5	6
14. I stick to my decisions about caring for myself even when I run into setbacks or problems	1	2	3	4	5	6
15. I know what I need to take care of myself..	1	2	3	4	5	6
16. If the doctor tells me to do something, I do it...	1	2	3	4	5	6
17. I take care of myself because my health is important to me.................................	1	2	3	4	5	6
18. I remember health care information about what I should do for myself	1	2	3	4	5	6
19. I know how much energy I need to take care of myself.......................................	1	2	3	4	5	6
20. To make a decision about my care, I look at both sides of my choices................	1	2	3	4	5	6
21. It matters to me that I care for myself..	1	2	3	4	5	6

Day of your birth/Last 4 digits of your social security number **Form B**

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day soc. sec. #

	Very Inaccurate				**Very Accurate**	
22. I know when I have the ability to obtain my nutritional supps and food	1	2	3	4	5	6
23. I know where to find good information I need to help me take care of myself	1	2	3	4	5	6
24. I think about how all the things I do fit together to help me reach my health goals	1	2	3	4	5	6
25. I have the ability to plan my nutritional needs	1	2	3	4	5	6
26. I fit new self-care actions into what I already do	1	2	3	4	5	6
27. My hearing and vision are good enough to allow me to care for myself	1	2	3	4	5	6
28. The way I take care of myself fits in with what I consider important in my life	1	2	3	4	5	6
29. I do what I know is best in taking care of myself even though I may not like it	1	2	3	4	5	6
30. I do my self-care in several different ways	1	2	3	4	5	6
31. I follow through with decisions I make about caring for myself	1	2	3	4	5	6
32. I have a set routine for caring for myself including meal planning	1	2	3	4	5	6
33. I think about how decisions I make will affect my health and self-care	1	2	3	4	5	6
34. I knowingly spend my energies on the most important self-care tasks	1	2	3	4	5	6
35. I use information from authorities to help me take better care of myself	1	2	3	4	5	6
36. I have the ability to prepare my meals	1	2	3	4	5	6
37. I think about several choices before I make a decision about my self-care	1	2	3	4	5	6
38. I know why I make the choices I do in order to care for myself	1	2	3	4	5	6
39. I know which actions to do first to best accomplish my self-care	1	2	3	4	5	6
40. Once I begin to care for myself in a certain way, I check to see if it is working	1	2	3	4	5	6
	Unhealthy				**Healthy**	
1. Using a scale of 1 to 6, how would you rate your health at this moment?	1	2	3	4	5	6
	Unhealthy				**Healthy**	
2. Using a scale of 1 to 6, how would you rate your own health in general?	1	2	3	4	5	6
	None				**All**	
3. Using a scale of 1 to 6, how much of your own care are you providing?	1	2	3	4	5	6

Personal Information	

Day of your birth/Last 4 digits of your social security number **Form B**

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day soc. sec. #

Age	☐ ☐
Gender	☐ Female ☐ Male
Current living arrangement	☐ alone ☐ with family in the same house ☐ with others in the same house
Ethnic group	☐ American Indian/Alaskan Native ☐ Asian/Pacific Islander ☐ Hispanic ☐ Black ☐ White ☐ Other
Who assists you with your self-care?	☐ no one ☐ me ☐ other family member(s) ☐ friends(s) ☐ nurse(s) ☐ housekeeper ☐ other
Are you currently taking any prescription medications?	☐ yes ☐ no
If yes, please list medications	
Do you need help in taking your medication? ☐ Yes ☐ No If yes, please describe the help given.	

Day of your birth/Last 4 digits of your social security number **Form B**

__ __ / __ __ __ __
day soc. sec. #

Personal Information	
Are you on a special diet?	☐ yes ☐ no
Examples include: 1. Who does your grocery shopping? 2. Do you have a grocery budget? 3. Who does the cooking? 4. Do you prepare meals? 5. Do you frequent take-out food? 6. Do you eat three meals a day?	
Last time seen by a health care professional (MD, nurse, Chiropractor, etc.)?	_____ Month _____ Year
If yes, please list the problem.	
List your diagnoses, if known, and length of time you have had this health problem.	

Day of your birth/Last 4 digits of your social security number **Form B**

__ __ / __ __ __ __
day soc. sec. #

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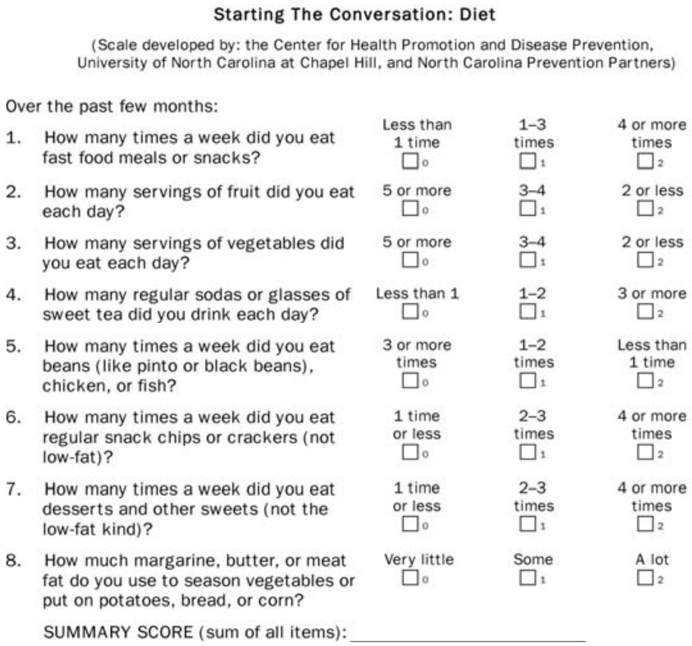
Attachment C

Table 2. - Starting the Conversation



Starting The Conversation: Diet

(Scale developed by: the Center for Health Promotion and Disease Prevention, University of North Carolina at Chapel Hill, and North Carolina Prevention Partners)

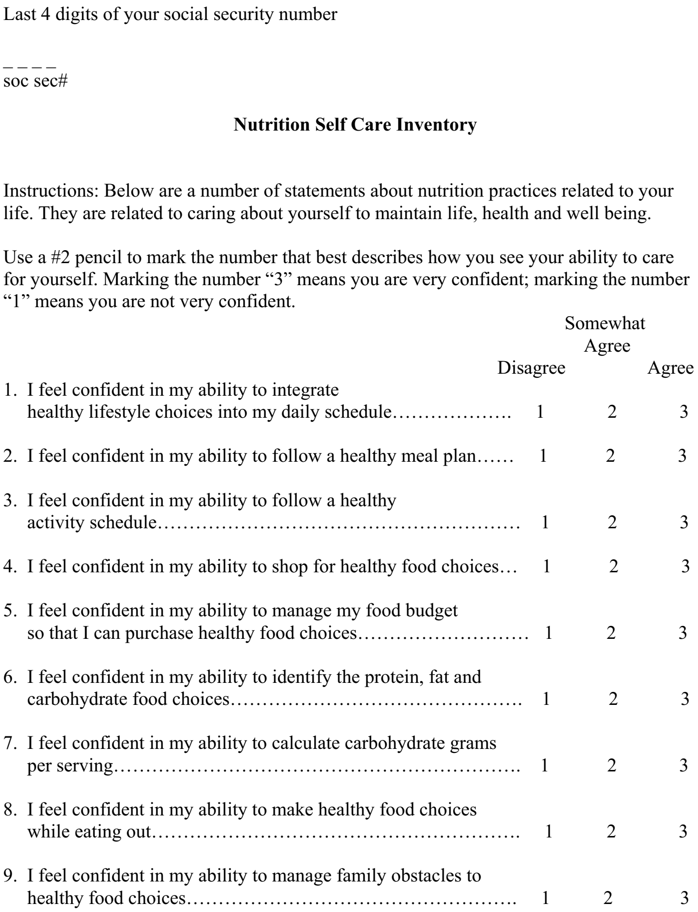
Over the past few months:

1.	How many times a week did you eat fast food meals or snacks?	Less than 1 time ☐ 0	1–3 times ☐ 1	4 or more times ☐ 2
2.	How many servings of fruit did you eat each day?	5 or more ☐ 0	3–4 ☐ 1	2 or less ☐ 2
3.	How many servings of vegetables did you eat each day?	5 or more ☐ 0	3–4 ☐ 1	2 or less ☐ 2
4.	How many regular sodas or glasses of sweet tea did you drink each day?	Less than 1 ☐ 0	1–2 ☐ 1	3 or more ☐ 2
5.	How many times a week did you eat beans (like pinto or black beans), chicken, or fish?	3 or more times ☐ 0	1–2 times ☐ 1	Less than 1 time ☐ 2
6.	How many times a week did you eat regular snack chips or crackers (not low-fat)?	1 time or less ☐ 0	2–3 times ☐ 1	4 or more times ☐ 2
7.	How many times a week did you eat desserts and other sweets (not the low-fat kind)?	1 time or less ☐ 0	2–3 times ☐ 1	4 or more times ☐ 2
8.	How much margarine, butter, or meat fat do you use to season vegetables or put on potatoes, bread, or corn?	Very little ☐ 0	Some ☐ 1	A lot ☐ 2

SUMMARY SCORE (sum of all items): ____________________

Attachment D

Table 3. - Nutrition Self Care Inventory



Last 4 digits of your social security number

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soc sec#

Nutrition Self Care Inventory

Instructions: Below are a number of statements about nutrition practices related to your life. They are related to caring about yourself to maintain life, health and well being.

Use a #2 pencil to mark the number that best describes how you see your ability to care for yourself. Marking the number "3" means you are very confident; marking the number "1" means you are not very confident.

	Disagree	Somewhat Agree	Agree
1. I feel confident in my ability to integrate healthy lifestyle choices into my daily schedule……………….	1	2	3
2. I feel confident in my ability to follow a healthy meal plan……	1	2	3
3. I feel confident in my ability to follow a healthy activity schedule…………………………………………………	1	2	3
4. I feel confident in my ability to shop for healthy food choices…	1	2	3
5. I feel confident in my ability to manage my food budget so that I can purchase healthy food choices………………………	1	2	3
6. I feel confident in my ability to identify the protein, fat and carbohydrate food choices……………………………………….	1	2	3
7. I feel confident in my ability to calculate carbohydrate grams per serving…………………………………………………….	1	2	3
8. I feel confident in my ability to make healthy food choices while eating out……………………………………………….	1	2	3
9. I feel confident in my ability to manage family obstacles to healthy food choices…………………………………………….	1	2	3

10. I feel confident in my ability to be satisfied with my healthy lifestyle choices……………………………………………… 1 2 3

Demographics

Vital signs ____________________

BMI ____________________

Age: _____

Gender: Male_____ Female_____

Race: Black_____ White_____ Hispanic_____ Other_____

Living arrangements: Self_____ Family_____ Roommate_____

Occupation: ________________________Hours worked per week______________

EXPLORING FACTORS RELATED TO HEALTHY AGEING

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ABSTRACT

As the population in the world ages, knowledge of healthy ageing is becoming more important. The April 2012 World Health Day, recognizes the importance of knowledge of healthy behaviors. This knowledge can support successful ageing and identify strategies to facilitate older adults leading productive lives in their homes and communities. Therefore, this phenomenological study exploring factors related to healthy ageing is timely. Using a qualitative methodology, elders were interviewed to discover perceptions of facilitators and barriers to healthy ageing. The following facilitators of successful ageing were revealed; taking care of self, positive attitude and meaningful activity. The barriers of successful ageing revealed were; giving up and giving in, ageing process and environmental limitations. Findings from this study can help guide nursing and supportive interventions to foster healthy ageing. Assumptions for this study are as follows: (a) People may indicate and explain their views in a one on one interview in ways that are less likely to occur in a focus group format, (b) Individual interviews may give a sense of security and encourage sharing to those who may be anxious about participating in a group experience, and (c) Elderly persons living independently are more healthy than elderly persons living in a dependent situation. The results revealed a number of limitations related to the methodology: small convenience sample size; the disproportionate percentage of female to male participants; participants from one geographical location. This research will inform nursing practice, influence public policy, and facilitate development of nursing curriculum in the care of older adults. Specifically, this research provided credible evidence necessitating future investigation regarding the self care barriers experienced by elders and heard through their voices. Basic conditioning factors related to environmental obstacles in healthy ageing were significant. Findings will be shared with policy makers and agencies supportive of community self care.

KEYWORDS

ageing, barriers, facilitators, self-care

1 INTRODUCTION

Successful healthy ageing is impacted by a healthy lifestyle and is positively related to a reduced mortality risk and a delay in health deterioration (Merrill, *et al.*, 2008). Healthy ageing is not limited to absence of disease and disability, "but as the reflection of the lived experience of daily life, as a capacity to engage meaningfully with and respond to the contingencies of daily life regardless of afflictions and disabilities" (Bryant *et al.*, 2001).

Understanding the older adult's perception of facilitators and barriers to healthy ageing is important to the practice of nursing and informs strategic planning that influences public policy, nursing curriculum, and nursing practice identifying self-care and meaningful activities supportive to elders in independent living.

The aim of this study was to explore the factors associated with healthy ageing through personal interviews. This phenomenological study utilizing Dorthea Orem's Self Care Nursing Theory (Orem, 1971), investigated older adults' (aged 80-95 years old) perceptions of facilitators and barriers to healthy ageing. Utilizing researcher led interviews and thematic outcome data evaluation; facilitators and barriers to healthy could be identified. This research format provides an important contribution to the body of knowledge. The research answered the knowledge gap giving voice to the elders regarding their impression of facilitators and barriers to healthy ageing. There is a paucity of research identifying facilitators and barriers to healthy ageing from the perspective of the elders.

The research identified three themes as facilitators to healthy ageing: taking care of self; meaningful activity; and positive attitude. Barriers to healthy ageing identified were: giving up or giving in; environmental limitations; and the ageing process. These findings are important in the development of supportive programs and elder services, specific to the themes identified, as well as to assessments of elders' current state of well-being and self-care agency. Programs and services that incorporate mechanisms for minimizing the barriers and supporting facilitators will promote improved care for community dwelling elders. A limitation of this study is the small sample size of 10 older adults living in an urban area in the southeastern United States. Thus, the findings may not be generalizable.

2 BACKGROUND

According to the World Health Organization (WHO) the world's population of people 60 years of age and older has doubled since 1980 and is forecast to reach 2 billion by 2050 (WHO, 2012). Healthy older people are integral members of family and society making important contributions within the fabric of life. Determinants of facilitators and barriers to healthy ageing may ensure elders are supported in both community and alternate living environments. The WHO recognizes the benefits of potential contributions elders make, yet ageing begets special health challenges for the 21st century. In an era of budget constraints, limited resources, and increased demands on health care and social resources, understanding how to support healthy ageing for elders is crucial. Importantly, health providers and communities must be prepared to meet the specific needs of older populations. This includes but is not limited to "training for health professionals on old-age care; preventing and managing age-associated chronic diseases; designing sustainable policies on long-term and palliative care; and developing age-friendly services and settings" (WHO, 2012, para 2).

The importance of healthy ageing is also reflected in the mission of the Center for Disease Control and Prevention (CDC) CDC Healthy Ageing Research Network (CDC-HAN, ND) and the European Union Active and Healthy Ageing partnership (ND). The mission of the CDC Healthy Ageing Research Network is "To better understand the determinants of healthy ageing in diverse populations and settings; to identify, develop, and evaluate programs and policies that promote healthy ageing; and to translate and disseminate research into effective and sustainable public health programs and policies throughout the nation (CDC, para. 4). Regions that utilize research to guide the development of programs, which support healthy ageing, can expect significant social and economic benefits. Understanding the facilitators and barriers of healthy ageing may engender global transformations, one community at a time.

The aim of the European Union Innovative Partnership (EUIP) is to "bring together key stakeholders to define a positive vision for ageing well, establish common priorities for innovation, to identify and address the barriers to innovation and to accelerate and scale up the introduction of relevant innovative solutions across Europe" (EUIP, 2010 - para 1). The EUIP has supported research into the factors associated with healthy ageing. One project is the EU-Integrated Project GEHA (Franceschi, *et al.*, 2008). The conclusion is that genetics play a vital role in healthy ageing. Studies of centagenarians support the role of genetics (Frisard *et al.*, 2007; Oswald, *et al.*, 2010). Other factors that have been identified include nutrition (Atlantis, *et al.*, 2008; Halvorsrud *et al.*, 2012; Hughes, Bennett, & Hetherington, 2007), physical activity (Stuart, Chard, Benvenuti, and Steinwachs, 2009)), and environment (Halvorsrud *et al.*, 2012; Iwarsson *et al.*, 2007; Oswold, *et al.* 2010). There is a paucity of qualitative research into the facilitators and barriers to healthy ageing examining the perceptions of the ageing individual.

3 RESEARCH METHODOLOGY

Sample and Setting

This phenomenological study was designed to examine perceptions of the elderly on the facilitators and barriers of healthy ageing. Phenomenological methodology is best suited to research that is looking at uncovering a deep understanding of the lived experience of everyday experiences (Burns & Grove, 2009; Fain, 2009). Semi structured interviews were conducted with elderly persons aged 80 years and above to explore participants' perspective on factors that facilitate healthy ageing and factors considered as barriers to healthy ageing. Semi-structured interviews using open-ended questions provide some organization for the researcher that aids in the collection of narrative experiences that explore a particular phenomenon of interest (Fawcett & Garity, 2009). The participants consisted of 10 persons ranging in age from 80 to 95; there were 7 women and 3 men. Qualitative research, by its nature, requires a small sample size to support the process of extracting thick, rich data (Lincoln & Guba, 1985). All interviews were conducted in the participants' home and were audiotaped and transcribed verbatim. Confidentiality was guaranteed by removing participants' last names from the transcripts.

Data Collection

Institutional Review Board (IRB) approval was obtained through the host institution. A purposive sample of 10 elderly persons agreed to participate in the study. Purposive sampling is appropriate when the researcher has knowledge of the population and can select participants that are living the phenomenon of interest (LoBiondo-Wood & Haber, 2006). Each participant was known to the researchers either through colleagues or sharing common interests such as church. The interviewer met each participant in his or her home and explained the purpose of the research. Participants were given a verbal and written explanation of the research reviewing the purpose of the study, outlining the risks and benefits of participation and, assurance of privacy and confidentiality. The interviewer answered any questions or concerns voiced at that time and participants were given the opportunity to withdraw from the study at this point. Participants wishing to proceed signed an informed consent to participate.

There was no time limit placed on the length of each interview. The interviewer continued until the participant felt they had nothing further to add related to the subject area. The times for each interview ranged from approximately 20 minutes to 30 minutes. Confidentiality was maintained throughout the study. The interviews were transcribed with last names eliminated and participant's transcription was labeled using their first name.

Interview Questions

Four semi-structured open-ended questions developed from a brief review of literature were used to generate discussion to clarify perceptions of healthy ageing. Although all questions addressed facilitators and barriers to healthy ageing, the questions were modified for appropriateness depending on whether the participant understood the nature of the question.

The interview questions were:

1. What do you think has contributed to your longevity?
2. What do you do to stay healthy?
3. What are the factors that help you remain active?
4. What are the barriers to remaining active?

Data Analysis

For this study, a modified method of Patton's (1987) analysis and interpretation of qualitative data was utilized. Patton recognized that the analysis brings order to the data, and interpretation involves attaching meaning and significance to the analysis. A typist transcribed the ten audiotapes verbatim. The researchers reviewed the research and interview questions generated during the conceptual phase of the qualitative process. The transcripts were read and reread independently by two of the researchers to obtain a feeling of familiarity for each participant's expressed meaning, to get a sense of the whole, and to provide interrater reliability. Patton (1987) recommended using a case approach in analyzing the data. All data from each case (interview) were organized and a case study was developed. The first participant's written transcript was reread with significant statements and thematic descriptions extracted and labeled. Patterns and themes were identified as they emerged from the data. For this study, DeSantis and Ugarriza's (2000) definition of theme was utilized. The researchers defined a theme as an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations. As such, a theme captures and unifies the nature or basis of an experience into a meaningful whole. Significant statements, thematic descriptions, and verbatim quotes were organized around each theme. This procedure was repeated for each interview.

Content analysis, the next step in Patton's (1987) approach, involved identifying coherent and important examples, themes, and patterns in the data. The data were labeled and a data index was established. Common themes emerged from the data as each interview was compared and contrasted.

4 FINDINGS AND DISCUSSIONS

The participants did not differ significantly with regards to perceptions of facilitators and barriers to healthy ageing. Three themes emerged across interviews relating to facilitators to healthy ageing.

Taking Care of Self

According to Orem (1995), when self-care is effectively performed, it maintains structural integrity and human functioning and contributes to human development. The person's ability to care for self requires "deliberate and purposive action" (Orem *et al.*, 2001) that culminates in health. Self-care agency is the power to care for self (Orem, 1971). All participants spoke of caring for self as a contributing factor to their longevity. They described eating a healthy diet, participating in regular exercise, socializing with others, meeting their spiritual needs, and, availing themselves of medical interventions as needed as important factors in remaining physically and emotionally healthy. Dottie stated, "I think just staying active does it because the less active I am, the less I can do." Francis noted that she "watched my diet, my whole life I have watched my diet." Mary talked about daily exercise and keeping busy, "you have to be up and going … I work six days a week, I walk six miles almost every day … if you can keep doing that, you're OK." Willie stated, "You have to keep active and keep your mind stimulated. We take the medicines we are supposed to … and intercourse with other people."

Positive Attitude

Orem identified three types of self-care requisites that provide the basis for self-care. Developmental self-care requisites bring about living conditions that support life and promote human progress toward maturity. Coping with developmental milestones like ageing can prevent damaging effects of human growth or mitigate its negative effects (Orem, Taylor & Renpenning, 2001). All participants discussed having a positive attitude as contributing to their longevity, mitigating effects of ageing, and contributing to health. Tom talked about "keeping a good state of mental health" and "becoming aware of how easy it is to get into trouble" as helping him to stay healthy and remain active. Francis noted that "not sitting around feeling sorry for myself" helped her to remain active. She discussed the importance of being responsible for oneself saying, "I don't have anybody saying you can't do this or you can't do that, so that's me."

Meaningful Activity

Universal self-care requisites are present in all human beings and are those things related to life processes. They include one's ability to maintain a sufficient intake of air, water and food, prevent hazards, and to achieve of balance of activity and rest (Orem, 1995). All participants discussed the need to take part in some type of meaningful activity. Some discussed the role employment plays in their ability to remain healthy. Martha talked about her years of hard work holding down two jobs simultaneously; "I did a lot of hard work … I worked for X and them I came home … (we) had a laundry store and after supper I would go over there and clean it up." Betty discussed the importance of activity in her life, "I go to Bible study … I go to meetings for the women's society and I go to the circle. I volunteer at the lighthouse … its fun and you are doing something worthwhile." Alfred stated, "I go to work. I go fishing. I do what I want. I have a garden. I stay busy." Many of the participants discussed how important doing something they enjoyed contributed to their sense of health and well-being and contributed meaning to their lives. Willie discussed being active and doing the things that keep him healthy and active. "Mentally I feel like I can do them." Francis noted, "I have to have something to get me up out of bed in the morning. I have a Monday card group … Tuesday night we go down to the beach and play cards … my biggest thing that I do is my tennis."

Three themes emerged across interviews relating to barriers to healthy ageing.

Giving In and Giving Up

Throughout the majority of interviews the one barrier identified as a concern was doing whatever they could to keep going and not to give up. Dottie stated, "I want to do it, but sometimes a lazy streak comes in there every once in a while. I like to do things but, sometimes I just want to vegetate and do nothing. It's all about attitude." Mary stated" I don't mind working. It gets me out of the house. It gets me with people all day long. I told the kids I might retire when I'm 85, but I have to have something to do. I have to have something else." A narrower social world is not satisfactory for Mary. Mary also stated, "I think you just have to get up and go or sit down and die. Nobody pushes you to do anything at my age and I think people would say not to do this or that, but that is the wrong attitude. You have to get up and go." Francis enjoyed the fact that, "I don't have to worry about another soul, except I have a son. But other than that I don't have anybody saying you can't do this or you can't do that." The ability of these participants to not give in or give up supported the Orem universal self-care requisites found in every human being across all stages of life, and involved with maintenance of both structure and function and general well-being (Orem, 1995). Willie summarizes this well by saying "I do think as you go through life anyway you have to have the fortitude or whatever, you have to be willing to get up and go again if something knocks you down, I learned that early on to get back up and keep going."

Ageing Process

Several of the participants discussed the important of living with the deleterious effects of ageing and compensatory medical treatment. According to Orem (1995), health deviations and resulting self-care requisites include not only effectively carrying out medically prescribed treatments as well as learning to live with the effects of illness and medical treatment. Tom stated, "I had a heart valve replacement and a stroke and while I got over it, I consequently had several bouts of congestive heart failure and dehydration put me in the hospital. I think that becoming very aware of how easy it is to get into trouble is probably one of the things that has made me able to live longer because I feel better than I had felt in a long time. I eat better; I watch my fluid because I have kidney failure, not serious so I would say that the period of illness that I had made me aware of what I needed to do to take care of myself and that probably has helped in getting me to last longer." Willie stated, "that being a natural chemistry that comes from the fact that my mother, she lived till she was 86 years old, so part of it is inheritance, I think. And we are fortunately able to afford the drugs that the doctors prescribe for us, and I honestly believe that chemistry is keeping all of us alive a lot longer than our previous generations because we take medicines we are suppose to and that wards off the other things that might come about".

Dottie stated, "My body betrays me sometimes, I guess by 81, you kind of slow down. You do just have to stay with it. If you don't stay with it, boy you are lost". Martha noted, "I've got a bad leg, and it doesn't keep me from walking but it keeps me from walking far." Although many of the participants spoke about slowing down with age or having medical conditions which require medications and physician treatment, they stressed the need to persevere.

Environmental Limitations

Many of the participants talked about the importance of their environment to remaining active and healthy and how environmental limitations can decrease one's quality of life. Tom was very articulate about the need for environmental modifications that support the lifestyles of the elderly. "To be active, means to be able to travel and do things. Unfortunately, when we travel, the people who claim to have handicap rooms have had the worst advice in the world. Numerous times I have been placed in situations where you can't sit down in the shower or if you get in the tub, you can't get out. Carpets are too deep for wheelchairs or electric carts to get through. Outlets are too low and there are never enough of them. If you have a clock and a light by the bed they take up all the outlets usually and you need a Continuous Positive Airway Pressure (CPAP) machine, humidifier and so forth. When they talk about handicap they really have no idea." Betty stated, "I am blessed to be living in this environment. Everything is so close, food is next door and there are no stairs." Similarly, Martha stated, "Everything is convenient. I don't have to climb stairs; there is room for my walker." Ann stated: "I cannot walk in the neighborhood because I am afraid of the dogs."

The themes and facilitators revealed in this research coincide with the Healthy People 2020 (2012) leading health indicators. The importance of taking care of self through medication and health care practitioner interventions was evidenced in the group interviewed. The positive attitude suggests support of previous research reporting longevity increased by positive perceptions of ageing (Levy *et al.*, 2002). Meaningful activity, or going and doing something meaningful (Bryant *et al.*, 2001) does contribute and is important to healthy ageing.

5 CONCLUSIONS AND FURTHER RESEARCH

The aim of this study was to examine the perceptions of the elderly on the facilitators and barriers of healthy ageing. Interviews with seven women and three men revealed both. While the sample size was small (n = 10) and represented a limited segment of the population in one area of the United States, several themes were identified. Thematic analysis of the guided interviews revealed facilitators and barriers to healthy ageing. The facilitator themes were; Taking Care of Self, Positive Attitude, and Meaningful Activity. Barriers to healthy ageing were; Giving In and Giving Up, Ageing Process, and Environmental Limitations. These themes build foundational evidence for future research related to healthy ageing.

This research informs nursing practice, may influence public policy, and facilitate development of nursing curriculum in the self-care and basic conditioning factors of older adults.

Specifically, this research provided credible evidence necessitating future investigation regarding the self care barriers experienced by elders and heard through their voices. Basic conditioning factors related to environmental obstacles in healthy ageing were significant. Findings will be shared with policy makers and agencies supportive of community self care.

Further research is needed to identify interventions tailored to fostering healthy ageing. Nursing interventions in the educative-supportive realm must include consideration of the individual, family, environment and health care system. Nursing care must include the recognition and assessment of self-care capabilities, the need for positive attitude and meaningful activities.

Public policies related to healthy ageing need to be addressed. As noted in the research and heard through the voices of the participants, the buildings and environments alleged to be in support of healthy ageing fail in many areas. In the United States, the Americans with Disabilities Act of 1990 requires that all public buildings meet code to allow for individuals with mobility limitations (Americans with Disabilities Act of 1990). Yet, these interviews revealed severe limitations for individuals in wheelchairs to go to public spaces such as hotels and restaurans Creating public policy and implementing changes to follow the ADA guidelines are needed in all public places to facilitate health ageing. Further research is needed to identify methods to foster public policies and creation of supportive environments.

Orem's (1995) Self-Care Deficit Nursing Theory (SCDNT) can provide the framework for further investigation and development of nursing interventions. According to the SCDNT, individuals will perform activities necessary to care for themselves. Persons have the ability for deliberate self-care, a goal-directed activity that is learned. The capacity to care for self is self-care agency (SCA). Interventions that will enhance SCA will facilitate healthy ageing and ameliorate barriers.

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DECISION-MAKING PROCESSES RELATED TO ADMINISTRATION OF ARTIFICIAL NUTRITION AND HYDRATION IN PATIENTS WITH DEMENTIA AT THE END OF LIFE. WHO DECIDES?

ENTSCHEIDUNGSFINDUNGSPROZESSE ÜBER EINE KÜNSTLICHE ERNÄHRUNG AM LEBENSENDE BEI PATIENTEN MIT DEMENZ - WER ENTSCHEIDET?

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ABSTRACT

Background: Nurses often have a close and trust-based relationship with patients with advanced dementia and their relatives during the end-of-life care process. As a result they become involved in complex ethical decision-making processes regarding artificial nutrition and hydration. Little is known about the nurses' role and how their work affects the decision-making process. Thus, the question is how precisely to define the role so as to understand their relational work.

Aims: To define the role of nurses in the decision-making process and clarify their involvement; to identify the influences different settings have on the decision-making process.

Design/Methods: Qualitative approach; 24 interviews with nurses in hospitals, nursing homes and home care services.

Results: Nurses' involvement varies significantly in the different care settings. Nurses in nursing homes take on an active and powerful role in the decision-making process while the nurses' role in acute care depends on the hierarchical structures of the given setting. In home care services, nurses pave the way for their patients to "die with dignity".

Conclusions: Nurses can make a valuable contribution to the decision-making process. While nurses in acute care and nursing homes do not use an ethical language to describe their involvement, nurses in home care services use the language of dignity. However, nurses' active work does not necessarily imply any moral reflection.

Relevance to Practical Implications: Nurses' involvement in decision-making is dependent on the setting, which needs to be considered and analyzed more in-depth. For nurses to fulfill their roles, their tasks and responsibilities in the decision-making process need to be spelt out clearly.

KEYWORDS

artificial nutrition, dementia, decision-making process, role of nursing, setting

ZUSAMMENFASSUNG

Hintergrund: Pflegende haben häufig eine enge und vertrauensvolle Beziehung zu Patienten mit fortgeschrittener Demenz sowie zu den Angehörigen im Versorgungsprozess am Lebensende. Sie sind deshalb in komplexe ethische Entscheidungsfindungsprozesse involviert. Dies betrifft auch die künstliche Ernährung. Es ist allerdings wenig darüber bekannt, auf welche Art und Weise sie ihre Rolle ausgestalten und welchen Einfluss ihr Handeln im Entscheidungsfindungsprozess nehmen kann. Dieser Artikel präsentiert Teilergebnisse einer Studie im Rahmen einer noch nicht vollständig abgeschlossenen Studie und fokussiert die Entscheidungsmacht der Pflegenden in den Pflegesettings Krankenhaus, Altenheim und ambulanter Pflege.

Ziele: Ziel der Untersuchung ist die Klärung der aktiven und passiven Teilhabe der Pflegenden im Entscheidungsfindungsprozess sowie die Identifikation von Einflussfaktoren in drei verschiedenen Settings: Krankenhaus, Altenpflegeheim und häusliche Pflege

Methoden: Gewählt wurde ein qualitatives Design. Es wurden 24 leitfadengestützte Interviews mit Pflegenden in Krankenhäusern, Altenheimen und in der ambulanten Pflege durchgeführt. Die Datensammlung und -analyse erfolgte nach einem in der Pflegewissenschaft von Bernadette Dierckx de Casterlé *et al.* (2011) neu entwickelten Ansatz der Grounded Theory Methodologie.

Ergebnisse: Während die aktive Teilhabe, respektive direkte Beteiligung der Pflegenden am Entscheidungsfindungsprozess begrenzt ist und der Handlungsspielraum als eng definiert werden kann, ist die passive Teilhabehabe, respektive indirekte Rolle, vielseitig und der Handlungsspielraum kann als relativ weit gefasst werden.

Pflegende agieren als Informanten, Begleiter und Advokaten von Patienten und Angehörigen. Dabei ist für sie der Wille der Patienten handlungsleitend. Die pflegerische Beteiligung ist abhängig vom jeweiligen Setting. Pflegende im Altenheim haben eine entscheidungsmächtige Rolle, während die Beteiligung der Pflegenden im Krankenhaus von der hierarchischen Struktur bestimmt wird. Im ambulanten Bereich ebnen die Pflegenden ihren Patienten den Weg für ein "würdevolles Sterben".

Diskussion und Zusammenfassung: Pflegende leisten einen einflussreichen Beitrag im Entscheidungsfindungsprozess und wollen als Teammitglied beteiligt sein. Dennoch impliziert das aktive Handeln der Pflegenden nicht notwendigerweise eine moralische Reflexion.

Relevanz der Studie und praktische Folgerungen: Die Beteiligung der Pflegenden am Entscheidungsfindungsprozess ist abhängig vom Setting und muss genauer beobachtet und detailliert analysiert werden. Damit die Pflegenden ihre Rollen ausfüllen können, müssen ihre Aufgaben und Verantwortungsbereiche im Entscheidungsfindungsprozess eindeutig definiert werden.

SCHLÜSSELBEGRIFFE

Demenz, Entscheidungsfindungsprozess, künstliche Ernährung, Rolle der Pflegenden, Setting

1 EINLEITUNG

Entscheidungen über eine künstliche Ernährung am Lebensende werden häufig bei Menschen mit Demenz im fortgeschrittenen Stadium der Erkrankung notwendig, wenn diese nicht mehr essen und trinken. Durch die weltweite Zunahme der demenziellen Erkrankungen von aktuell 35,6 Millionen (Deutsche Alzheimer Gesellschaft, 2012) auf prognostizierte 81 Millionen bis zum Jahr 2040 (Ferri *et al.*, 2005) rückt die Diskussion der künstlichen Ernährung dieser Menschen in den Brennpunkt des gesellschaftlichen, gesundheitspolitischen und ethischen Interesses. Die betroffenen Angehörigen der meist entscheidungsunfähigen Patienten, die behandelnden Ärzte und Pflegenden, die mit der Entscheidung über eine künstliche Ernährung konfrontiert werden, sind fachlich, ethisch und emotional herausgefordert (Bryon *et al.*, 2010; Lopez *et al.*, 2010; Mitchell, 2007; Synofzik, 2007; Oberle and Hughes, 2000), weil die zu treffende Entscheidung eine lebensnotwendige ist und die Vorstellung des Verhungern- und Verdursten-Lassens kaum vereinbar mit kulturellen und religiösen Wertvorstellungen ist.

Die Pflegenden betrachten die Bereitstellung von Nahrung und Flüssigkeit und die Hilfestellung beim Essen und Trinken als originäre Pflegetätigkeit. Zu ihren schwerkranken Patienten haben sie meist eine enge und vertrauensvolle Beziehung und werden dadurch in die komplexen Entscheidungsfindungsprozesse zur künstlichen Ernährung und Flüssigkeitszufuhr involviert (Haas and Kohlen, 2010). Sie sehen sich zum einen mit ihren dementen Patienten konfrontiert, die nicht mehr essen und deren Willensbekundungen oft nicht eindeutig sind. Zum anderen werden sie häufig von verunsicherten Angehörigen um Rat gefragt und letztlich sollen sie ärztliche Entscheidungen mit umsetzten, die manchmal ihren eigenen Einschätzungen widersprechen.

Die Rolle der Pflegenden im Entscheidungsfindungsprozess zeigt sich in ihrer Interaktion mit allen am Entscheidungsprozess Beteiligten. In der aktuellen Studie werden Pflegende zu ihrer Rolle bei der Entscheidungsfindung über eine künstliche Ernährung 4) mittels einer perkutanen endoskopischen Gastrostomie (PEG) bei dementen Menschen am Lebensende befragt. Ihre Fallschilderungen machen ihre Rollen im Entscheidungsfindungsprozess an ihrem Handeln sichtbar. Es ist notwendig, die Rollen der Pflegenden in Entscheidungsfindungsprozessen am Lebensende empirisch zu untersuchen, denn erst das Wissen darüber, wie die Pflegenden in Entscheidungsfindungsprozesse handeln, welches Erfahrungswissen und welche ethischen Annahmen sie leiten, schaffen die Basis für eine konkrete Verantwortungs- und Rollenzuschreibung im Entscheidungsfindungsprozess.

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4) *Im Folgenden steht "künstliche Ernährung" für die Zufuhr von Nährstoffen und Flüssigkeit über eine PEG-Sonde.*

2 IDENTIFIKATION DER FORSCHUNGSLÜCKE

Die Entscheidung über eine künstliche Ernährung fällt in den Verantwortungsbereich des Arztes (Pasman *et al.*, 2004; Bryon *et al.,* 2010). Pflegende haben nur einen begrenzten direkten Einfluss auf diese Entscheidung. Durch ihre Nähe zum Patienten, sind sie jedoch in der Lage eine einflussreiche indirekte Rolle einzunehmen. Indem sie Veränderungen wahrnehmen und Informationen weiterleiten, initiieren und begleiten sie häufig den Entscheidungsprozess (Bryon *et al.*, 2008; Bryon *et al.*, 2010).

Die passive pflegerische Rolle im Entscheidungsfindungsprozess zur PEG ist facettenreich; die Pflegenden agieren als Informationsvermittler, Unterstützer und Advokaten (Adams *et al.*, 2011). Als Vermittler geben sie Informationen über den Patienten an Angehörige und das Behandlungsteam weiter, koordinieren Gespräche (Silén *et al.*, 2008; McMillen, 2008; Kennard, 1996) und schaffen sich so eine "Schlüsselstellung" unter allen Beteiligten bei der Entscheidungsfindung (Dinand, 2012, 151). Die Pflegenden entwickeln ein genaues Bild von den dementen Patienten. Sie sind berührt von deren Vulnerabilität und wollen durch ihre "good care" diese Verletzlichkeit limitieren und die Würde, Integrität und Autonomie der Patienten wahren. "Good care" schließt die Sterbebegleitung und die Begleitung der Familie ein (Bryon *et al.*, 2010). Die pflegerische Unterstützung erstreckt sich auf die Beratung, Anleitung und Begleitung der Patienten und deren Angehörigen und die Pflegenden sehen sich als Wegbegleiter der alten Menschen (Dinand, 2012, 151).

3 ZIEL UND FRAGESTELLUNG

Angesichts der oben dargestellten komplexen Entscheidungsproblematik über eine künstliche Ernährung bei Menschen mit fortgeschrittener Demenz und der entscheidenden Position der Pflegenden in der Versorgung, erscheint es notwendig, die Aufgaben der Pflegenden im Entscheidungsfindungsprozess zu klären. Erst die Erkenntnisse darüber, wie die Pflegenden im Entscheidungsfindungsprozess handeln und welches Erfahrungswissen und welche ethischen Annahmen sie leiten, schaffen die Basis für eine konkrete Verantwortungs- und Rollenzuschreibung im Entscheidungsfindungsprozess. Die Rolle der Pflegenden im Entscheidungsfindungsprozess über eine künstliche Ernährung am Lebensende bei Patienten mit Demenz wird in den folgenden Settings untersucht: Krankenhaus, Altenheim und Ambulante Pflege.

Die Forschungsfragen sind:

Welche Rolle nehmen die Pflegenden im Entscheidungsfindungsprozess zur künstlichen Ernährung bei Menschen mit Demenz ein?

Wie zeigt sich ihre Rolleneinnahme in ihrem Pflegehandeln?

Es ist das Ziel, Gemeinsamkeiten und Unterschiede des pflegerischen Handelns in den individuellen Entscheidungsfindungsprozessen und in den verschiedenen Settings zu erkennen und möglicherweise vorhandene pflegerische Konzepte, die sich im Handeln zeigen, offen zu legen. In diesem Artikel werden Teilergebnisse einer drei Jahre umfassenden qualitativen Studie vorgestellt. Sie zeigen, wer tatsächlich in den verschiedenen Settings entscheidet. Machtfragen werden hierbei offenbar.

4 METHODOLOGIE

Vor dem Hintergrund des gegenwärtigen Forschungsstandes wurde die Frage zu der hiesigen Studie entwickelt. Zentral geht es um das tatsächliche Handeln der Pflegenden. Es wurde ein Zugang zum Forschungsfeld gewählt, der die Sicht der Befragten offen legt und anhand der Beschreibung ihres Handels in der Praxis möglicherweise dahinter liegende Konzepte erkennen lässt. Deshalb war die Methode der Wahl für Datensammlung und -analyse die Grounded Theory Methodologie (GTM).

Die GTM wurde vor 45 Jahren von den amerikanischen Soziologen Barney Glaser und Anselm Strauss aus ihrer Forschungsarbeit heraus zur Generierung von Theorien entwickelt und versteht sich als eine praxisnahe Konzeption, die eine nachvollziehende und systematische Reflexion einer konkreten Forschungsarbeit ermöglicht. Die GTM wurde bis heute zu einem facettenreichen Forschungsansatz weiterentwickelt und gehört zu den prominentesten Forschungsstilen im so genannten Werkzeugkasten der qualitativen Sozialforschung (Mruck and Mey, 2007). Eine Ausdifferenzierung der GTM stellen Bernadette Dierckx de Casterlé, Chris Gastmans, Els Bryon und Yvonne Denier (2011) mit der von ihnen entwickelten Analysemethode QUAGOL (Qualitative Analysis Guide of Leuven) vor, durch deren Anwendung der Analyseprozess innerhalb der GTM operationalisiert wird. Dierckx de Casterlé *et al.* erkannten die Notwendigkeit eines Ansatzes, der den Forscher bei der Datenanalyse unterstützt, ohne eine starre Schritt-für-Schritt-Vorgehensweise vorzuschreiben. Vielmehr soll es dem Forscher möglich sein, die Bedeutung der Daten auf einem wissenschaftlich-konstanten Weg zu verstehen und gleichzeitig sollen Intuition, Vorstellung und Kreativität einbezogen werden (Dierckx de Casterlé *et al.*, 2011). Die Datenanalyse nach QUAGOL sieht zwei aufeinander folgende Arbeitsschritte vor: die Vorbereitung der Datenkodierung und den sich daran anschließenden Kodierungsprozess mit einem Softwareprogramm. Dadurch wird die Fragmentierung der Daten vermieden und die Unversehrtheit der Geschichte gewährleistet (Dierckx de Casterlé *et al.*, 2011). "Die drei Essentials der GTM" (Mruck and Mey, 2007), nämlich Konzeptbildung statt Beschreibung, "Theoretical Sampling" und "Theroretical Saturation" sowie das Schreiben von Memos, sind dabei zentrale Arbeitsschritte. Aus Interviewgeschichten werden Essenzen gewonnen, die auf einer konzeptionellen Ebene gegen Konzepte ausgetauscht werden und im konstanten Vergleichsprozess zur

Identifikation von gemeinsamen Themen, Konzepten und Hypothesen führen können (Dierckx de Casterlé *et al.*, 2011).

Vorgehen und Stichprobe

Für die vorliegende explorative Untersuchung wurden drei unterschiedliche Settings (Krankenhäuser, Altenheime und ambulante Pflegedienste) ausgewählt, um ein möglichst breites Spektrum der Orte, an denen Pflege stattfindet, zu erfassen. Die Auswahl der Institutionen erfolgte nach zuvor festgelegten Kriterien (Größe, Trägerschaft, konfessionelle Ausrichtung und Lage), die der Vielfalt und Verschiedenheit der Einrichtungen Rechnung trugen. Die Stichprobenerhebung fand an drei Akutkrankenhäusern, einem psychiatrischen Krankenhaus, drei Altenheimen und in vier ambulanten Pflegediensten statt, die zum Teil in der Großstadt und zum Teil im ländlichen Umfeld angesiedelt sind.

Die Kontaktaufnahme erfolgte im persönlichen Gespräch der Autorin mit den jeweiligen Personen in der Geschäfts- oder Pflegedienstdirektion. Alle angefragten Personen erklärten sich bereit, an der Studie teilzunehmen und erhielten schriftliche Informationen über die geplanten Gespräche mit den Pflegenden. Sie benannten Kontaktpersonen, die als Bindeglied zwischen der Autorin und den Pflegenden fungierten. Diese Kontaktpersonen suchten dann Pflegende aus, die den vorher festgelegten Einschlusskriterien entsprachen: (1) Die Pflegenden sollten im letzten Jahr mit mindestens einer PEG-Entscheidung bei einem Patienten mit Demenz konfrontiert gewesen sein und (2) sie sollten bereit sein, am Interview teilzunehmen. Die Pflegenden erhielten von der Autorin Informationen über das geplante Gespräch und konnten Termin und Ort für das Interview frei wählen. Unmittelbar vor den Gesprächen unterzeichneten die Pflegenden eine vorbereitete schriftliche Einverständniserklärung und beantworten Fragen zu persönlichen Merkmalen (Alter, berufliche Qualifikation, Berufserfahrung und Arbeitsbereich), die von der Autorin notiert wurden. Die Stichprobe setzte sich aus 19 Frauen und fünf Männern zusammen. Die Alterspanne reichte von 28 bis 54 Jahre. Von den Pflegenden im Krankenhaus (n=8) arbeiten drei auf gastroenterologischen Stationen, zwei auf Stationen für geriatrische Rehabilitation, jeweils eine Pflegeperson auf einer nephrologischen, einer gerontopsychiatrischen und einer Intensivstation. Die Pflegenden in den Altenheimen (n=8) sind auf verschiedenen Bereichen der Langzeitpflege eingesetzt, die Pflegenden im ambulanten Bereich (n=8) hatten festgelegte Einsatzgebiete und einen fixen Patientenstamm. 23 (n=23) Pflegende besitzen eine Ausbildung in der Gesundheits- und Krankenpflege, eine Pflegeperson (n=1) hat eine Altenpflegeausbildung. Von den Pflegenden haben 22 (n=22) mindestens eine pflegerische Weiterbildung (Pflegedienstleitung, Stations-/Bereichsleitung, Palliative Care, Geriatrische Pflege, Praxisanleiter) und zwei ein pflegerisches Studium (Pflegemanagement) absolviert.

Datensammlung

Zwischen April 2010 und Dezember 2011 wurden 24 halbstrukturierte Interviews geführt, die zwischen 30 Minuten und 104 Minuten (59 Minuten im Durchschnitt) dauerten. Es waren 20 Einzelinterviews und ein Gruppeninterview mit vier Pflegenden. Zu Beginn der Interviews wurden die Pflegenden gefragt, wann sie zuletzt in die Pflege eines Patienten mit Demenz eingebunden waren, bei dem eine Entscheidung über eine PEG-Anlage anstand. Die Pflegenden wurden gebeten, diese Fallgeschichte zu schildern. Durch Nachfragen ergründete die Autorin die Schilderungen der Pflegenden noch tiefer und fokussierte ihre Erfahrungen und ihre Sichtweisen auf ihre Beteiligung im Entscheidungsprozess. Die Pflegenden konnten weitere Fälle schildern, die Ähnlichkeiten oder Unterschiede in der Entscheidungsfindung über eine PEG-Anlage aufwiesen. Der verwendete Interviewleitfaden wurde auf Grundlage der vorangegangen Literaturrecherche erstellt, in einem Pretest getestet und während des Forschungsprojektes kontinuierlich weiterentwickelt und angepasst. Die Interviews fanden auf Wunsch der Pflegenden an deren Arbeitsplatz statt.

Ethische Überlegungen

Alle beteiligten Institutionen, Kontaktpersonen und interviewten Pflegenden erhielten mündliche und schriftliche Informationen über die Studie. Die Teilnahme war freiwillig. Die Pflegenden unterzeichneten vor dem Gespräch eine schriftliche Einverständniserklärung. Ein Ausstieg aus der Studie war für die Pflegenden zu jeder Zeit möglich. Die Anonymität Institutionen und der Pflegenden wurde dadurch gewahrt, dass die Forscherin alle Gespräche persönlich führte, die Tonbandaufzeichnungen selbst transkribierte, anonymisierte und die Aufzeichnungen danach wieder löschte.

Datenanalyse

Die Datenanalyse begann unmittelbar nach den ersten Interviews und erfolgte nach der QUAGOL-Methode (Dierckx de Casterlé *et al.*, 2011). Die Gespräche wurden wiederholt gelesen, um einen Eindruck zum Inhalt und markanten Aussagen zu erhalten. Danach erfolgte die Transkription der Gespräche, wichtige Textpassagen wurden gekennzeichnet, Leitgedanken in Codes zusammengefasst, eine erste schrittweise Formulierung von Konzepten begonnen. Von jedem Interview wurde eine stichhaltige Reflexion formuliert, in der Konzepte zusammengefasst wurden. Danach wurden Kategorien gebildet und beschrieben. Auf dieser Basis dieser stichhaltigen Reflexionen konnten dann Zusammenhänge formuliert werden. Die Interviews wurden immer wieder gelesen, um stichhaltige Reflexionen zu verifizieren. Die bereits formulierten Reflexionen wurden mit neu gewonnenen Daten in Beziehung gesetzt und zum Teil weiterentwickelt. Die Analysen wurden bis zur Sättigung fortgeführt und die Datenverarbeitung wurde durch das PC-Programm MAXQDA unterstützt.

5 ERGEBNISSE UND DISKUSSION

Die Pflegenden sind im Rahmen der Versorgung ihrer demenziell erkrankten Patienten am Lebensende auf vielfältige Weise in den Entscheidungsfindungsprozess über eine künstliche Ernährung eingebunden. Wie sie ihren Einbezug in den Entscheidungsfindungsprozess ausgestalten, wird in ihren Fallschilderungen deutlich. Sie berichten darin von ihren Beziehungen zu den Patienten und deren Angehörigen, von der Zusammenarbeit mit den Ärzten und anderen Pflegenden im Team und sie beschreiben ihr Pflegehandeln.

Die erlebte Teilhabe im Entscheidungsfindungsprozess ist breit gefächert, wobei das Pflegesetting eine entscheidende Rolle spielt. Obwohl die Pflegenden in den verschiedenen Einrichtungen ganz unterschiedlich bei den Entscheidungen über eine künstliche Ernährung ihrer Patienten beteiligt sind, zieht sich ein roter Faden durch ihr Pflegehandeln: Sie erkennen in ihren demenziell erkrankten Patienten Menschen am Lebensende, die ihrer Hilfe bedürfen. Dadurch sehen sie sich aufgefordert, Sorge dafür zu tragen, dass der Wille der ihnen anvertrauten Menschen respektiert und umgesetzt wird. Viele Pflegende möchten ihren Patienten ein "würdevolles Sterben" ermöglichen. Dieser Anspruch ist die Maxime ihres pflegerischen Handelns.

> *"Ja, ich denke mir auch, wenn es ans Lebensende geht, also da ist eine Unsicherheit da. Manchmal wollen sie so an die Hand genommen werden. Wenn das nachher alles so läuft, dass es was Rundes ist, ja, und, wie soll ich sagen, positiv in Erinnerung bleibt, dann ist es natürlich was Schönes. Und das ist es auch, was uns beflügelt, also was… deswegen machen wir das ja. Also, jetzt auch hier, wo die Frau das Essen eingestellt hat, von sich aus, und er … da haben wir ja auch ganz intensiv den Ehemann begleitet, ja. Und der konnte es dann prima tragen, ja?" (P14)*

Im Entscheidungsfindungsprozess nehmen die Pflegenden vielfältige Rollen ein. Sie sind Initiatoren, Vermittler, Berater, Begleiter, Entscheider, Beobachter und Fürsprecher. Die Pflegenden sehen die Entscheidungsfindung über eine künstliche Ernährung eingebettet in ihrem umfassenden Pflegeauftrag, der weit über die eigentliche Entscheidung hinaus geht und sich auf den gesamten Entscheidungs- und Versorgungsprozess erstreckt. Unabhängig von der letztendlich getroffenen Entscheidung über die künstliche Ernährung, betreuen und begleiten die Pflegenden Patienten und Angehörige auch nach der Entscheidung und häufig auch im Sterbeprozess.

> *"Ich versuche immer die Leute zu bestärken. Das Ganze ist ja so mit Angst besetzt, weil wir diese Kultur nicht mehr, also, … in Italien oder in anderen Ländern ist es ja doch viel verwurzelter. .... Tod macht einfach Angst und den schickt man dann davon. Aber wenn, man*

> *jemanden hat, der einem Weg aufzeigt und einem zeigt, wie man den zu gehen hat oder gehen kann, eine Möglichkeit aufzeigt. Und dann wird das wie so ein Strohhalm. Und deswegen haben wir auch die Möglichkeit da sehr stark einzuwirken. Und das ist für uns sehr, sehr positiv.*" (P14)

5.1 Gemeinsamkeiten in den verschiedenen *Settings*

Alle Pflegende in allen *Settings* fanden es wichtig über Entscheidungen am Lebensende zu sprechen. Ihre Fallschilderungen waren detailliert, und sie konnten die Patienten, das Umfeld, die Zuständigkeiten im Entscheidungsprozess und ihr pflegerisches Handeln ausführlich beschreiben.

Das Verantwortungsbewusstsein der Pflegenden für die dementen Patienten ist unabhängig von der Dauer des pflegerischen Auftrages. Im Krankenhaus, wo die Patienten auf einigen Stationen nur zum Legen der Sonde kommen und nach wenigen Tagen entlassen werden oder versterben, sind die Pflegenden ebenso darauf bedacht, den Wünschen der Patienten gerecht zu werden, wie im Altenheim oder in der ambulanten Pflege, wo vor der Entscheidung oft schon über lange Zeit ein pflegerisches Verhältnis besteht. Alle Pflegenden wollen in den Entscheidungsfindungsprozess eingebunden werden. Viele sehen sich als "Experten" am Patientenbett. Sie sagen, dass sie durch ihre Nähe zum Patienten Veränderungen frühzeitig erkennen und durch ihre Erfahrung professionell beurteilen können.

Der mutmaßliche Wille des Patienten ist handlungsleitend

Die meisten Pflegenden sehen die Entscheidung über eine künstliche Ernährung am Lebensende als eine individuelle, die sorgsam bei jedem Patienten neu durchdacht und gefällt werden muss. Durch ihren engen Kontakt zu ihren Patienten und ihre Erfahrung entwickeln sie eine persönliche Einschätzung der Situation des Patienten. Diese persönliche Einschätzung ordnen sie jedoch dem Willen des Patienten unter. Seine Entscheidung zählt für sie absolut. In schwierigen Situationen, in denen Patienten sich nicht mehr äußern können, sind die Pflegenden bemüht den mutmaßlichen Willen zu ergründen. So interpretieren sie z.B. das ablehnende Verhalten eines Patienten bei der Nahrungsaufnahme als Willensbekundung sterben zu wollen. Die Pflegenden messen die Güte einer Entscheidung über eine künstliche Ernährung daran, ob der (mutmaßliche) Wille des Patienten berücksichtigt wurde. Entsprechen die Entscheidungen dem Willen der Patienten, dann werden sie von den Pflegenden akzeptiert.

> "*… ich hatte hier letztens eine Dame hier, die hat sich gegen eine PEG-Anlage bei ihrem Mann entschieden. … Sie sagt, ihr Mann und sie, waren leidenschaftliche Gärtner, immer unterwegs und er würde so*

> *nicht leben wollen. … Und das hat sie manchmal, immer so in den Raum gestreut, und dann habe ich gedacht, das ist eine tolle Entscheidung, dass sie sich so für ihren Mann entsetzt, wo ich mir vorstellen kann, wie schwer das ist, solche Entscheidungen am Bett zu treffen.*" *(P6)*

In solchen Fällen geben die Pflegenden den Angehörigen Unterstützung, indem sie sie in ihrer Entscheidung bestärken und sowohl den Patienten als auch die Angehörigen betreuen und begleiten. So versorgen die Pflegenden die Angehörigen z.B. mit umfassenden Informationen zu Vor -und Nachteilen einer PEG und möglichen Alternativen, damit diese gut vorbereitet sind für schwierige Entscheidungsgespräche im Familienkreis.

> "*… da fühlen die (Angehörigen) sich so ein bisschen gestärkt und nicht so alleine gelassen. Auch mit der Sonde halt, weil sie ein schlechtes Gewissen haben. Ich habe jetzt Verantwortung und jetzt bin ich schuld, wenn der stirbt. Und wenn sie von mir noch mal so ein bisschen Rückendeckung kriegen, dann … dann ist das leichter.*" *(P9)*

Einige Pflegende berichteten, dass der Wille der Patienten von den Ärzten oder den Angehörigen ignoriert wurde. Das waren Situationen in denen sich z.B. die Kinder über eine vorhandene Patientenverfügung hinweg setzten oder eine Eilbetreuung eingerichtet wurde, um den Wunsch einer demenziell erkrankten Patientin außer Kraft zu setzen. Die Fallschilderungen dieser Pflegenden sind gekennzeichnet von tiefer emotionaler Betroffenheit. Sie äußern Wut, Schuldgefühle und Machtlosigkeit, wenn sie die, in ihren Augen für die betroffenen Patienten falsche Entscheidung für eine PEG-Anlage hinnehmen müssen und ihre Patienten nicht nach deren Willen und ihrem pflegerischen Verständnis am Lebensende begleiten können. Andere Pflegende wehren sich gegen die Entscheidungen, indem sie veranlassen, dass eine ethische Fallbesprechung einberufen wird oder sie bringen "ihre Fallgeschichte" im Ethikforum zur Sprache.

> "*Der Mann war bei uns fünf Wochen, über fünf Wochen. Dann hieß es PEG. Dann hat er gesagt, nein das will er nicht. Dann haben sie es doch noch Mal versucht. Es gibt ja immer noch mehr engagierte ehrgeizige Ärzte, die glauben, man muss wirklich …ja? …. dann gab es ein Ethikgespräch. Und das fand ich sehr beeindruckend. Es war ein sehr patientenorientiertes, menschorientiertes Gespräch. Kann man das so sagen? Ich sage menschorientiert.*"*(P6)*

5.2 Unterschiede in den verschiedenen Settings

Der aktive Einbezug der Pflegenden in die Entscheidungsfindung unterscheidet sich in den Settings Krankenhaus, Altenheim und ambulante Pflege deutlich.

Im Krankenhaus: Die Entscheidung liegt bei den Ärzten

Abhängig von den Fachdisziplinen innerhalb der Krankenhäuser kann festgestellt werden, dass die Pflegenden im Krankenhaus den geringsten Einfluss auf die Entscheidungsfindung haben. Die Entscheidungen sind nicht nur arztdominiert, sondern auch abhängig von der Person und Position des Arztes. Die Beobachtungen und Einschätzungen der Pflegenden zur Situation der Patienten finden bei den Arztentscheidungen häufig keine Berücksichtigung. Viele Pflegende resignieren deshalb frustriert beugen sich der Entscheidung, indem sie diese hinnehmen, ihre Patienten aber unabhängig von der Entscheidung bestmöglich versorgen. Andere Pflegenden versuchen heimlich über die Angehörigen Einfluss auf die Entscheidung zu nehmen.

> *"Schwierig ist das immer … Man kann das vielleicht durch die Blume mit den Angehörigen besprechen, weil, ich glaub, man hat als Schwester ganz schlechte Karten, wenn man da irgendwas äußert. Man weiß ja auch nie, wie die Angehörigen reagieren. Und wie die das also hier mitteilen, den Ärzten. Ich glaube, da hätte man schlechte Karten, wenn der Oberarzt raus bekäme, dass man jetzt also versucht, die Angehörigen vielleicht von dieser Entscheidung also wegzubekommen, ja? … Mit den Stationsärzten kann man schon viel eher mal darüber diskutieren, ja aber letztendlich hat das mehr oder weniger keine Konsequenz, weil die schon auch davon abhängig sind, wie der Oberarzt entscheidet."* (P 2)

Anders stellt sich die Situation auf den geriatrischen und gerontopsychiatrischen Stationen der Krankenhäuser dar. Hier sind Gesprächskulturen implementiert, die es den Pflegenden ermöglichen, sich aktiv in den Entscheidungsfindungsprozess einzubringen. Es gibt Konzepte und Assessments zur Erfassung des mutmaßlichen Patientenwillens und Leitfäden, z.B. zur PEG- Entscheidung, die als Diskussionsgrundlage im multidisziplinären Team eingesetzt werden.

> *"Die Morgenrunde gehört zu unserem geriatrischen Konzept. Wir sprechen im Team über die Patienten. Team, das heißt dann alle. Wir, die Pflegenden, der Oberarzt, die Therapeuten. Da werden auch solche Beobachtungen besprochen, wenn jemand keine Fortschritte macht, im Gegenteil vielleicht abbaut, nur noch teilnahmslos im Bett liegt …und auch weniger isst. Ja. .... Ja. Wir haben durchaus auch hin und wieder in unseren Morgenrunden die Diskussion ob der Demenzpatient nicht eher, ja ... ein PEG-Patient wäre, wo man das anlegen könnte."* (P 4)

Im Altenheim: Die Entscheidung liegt bei den Pflegenden

Die Pflegenden in den Altenheimen haben oft eine verdeckte Entscheidungsmacht. Der weitgehend arztfreie Raum, der oft über lange Zeit bestehende Pflegeauftrag und die Vertrautheit mit dem Bewohner und den Angehörigen bieten ihnen ideale Voraussetzungen, zu entscheiden, welche Beobachtungen und Einschätzungen sie wann und in welchem Umfang an Hausarzt und Familie weitergeben. Selbst wenn die endgültige Entscheidung über eine künstliche Ernährung vom Arzt und den Angehörigen getroffen wird, kommt die Macht der Pflegenden zum Zuge, wenn sie nach ihrer Einschätzung der Situation des Patienten den Entscheidungsfindungsprozess zu initiieren. Die Pflegenden sind zufrieden, wenn die Entscheidung über eine künstliche Ernährung gemäß ihrer eigenen Einschätzung zum Wohle des Bewohners gefällt wird.

> *"Und dann kam die Tochter, ganz verzweifelt zu uns und sagte: "Was soll ich machen, die haben gesagt, wir müssen meiner Mutter eine PEG legen. Die isst und trinkt nicht mehr und die soll eine PEG kriegen." Die wog damals 47 Kilo und da haben wir gesagt: "Nein." …Die Mutter, wie gesagt, war völlig dement, war eine Frau voller Ängste, dann weiß ich nicht, welchen Gefallen ich jemanden tue, der dann vielleicht über diese Form der Nahrungsverweigerung, aus welchen Gründen auch immer, seinem Leben ein natürliches Ende setzen kann? … Da haben wir damals der Tochter abgeraten. Die Tochter hat auch dem entsprochen …." (P 8)*

Im häuslichen Bereich: Die Entscheidung liegt bei den Angehörigen

Die Pflegenden der ambulanten Pflegdienste berichten, dass die Entscheidungen über eine künstliche Ernährung eine Familienangelegenheit ist. Oft gibt es eine gute Zusammenarbeit mit den betreuenden Hausärzten und den Pflegediensten. Die Patienten sind häufig seit langem bekannt und zwischen den Familien und den Pflegenden hat sich im Laufe der Zeit ein Vertrauensverhältnis entwickelt. Die Pflegenden werden dann um Rat gefragt und begleiten die Familien bei der Entscheidungsfindung, indem sie die Angehörigen z.B. "an einen Tisch bringen" und eine Familienkonferenz moderieren.

> *"Jetzt gab es aber noch engagierte Kinder mit deren Partnern und noch drei Enkel, die auch schon erwachsen waren. Und die gesagt haben: Also so einfach entscheiden wir das nicht. Und die riefen dann bei mir an und haben gefragt: Was können wir denn jetzt machen? … Das hätte er wohl nie gewollt. ... .Und wir haben dann eine Familienkonferenz einberufen, in der alle da waren, wo ich sozusagen die Moderation des Gespräches übernommen habe. … Und das hat dann die Familie insofern gestärkt, dass sie den Vater nach Hause holen konnten und dass er dann dort noch eine Woche im Kreis seiner Lieben war, die sich wirklich rührend gekümmert haben, nur wenig Hilfe vom Pflegedienst brauchten und alles andere selbst übernommen haben. Und da gesund mit umgehen konnten." (P 18)*

Die Pflegenden in der ambulanten Pflege thematisieren die Entscheidungsfindung über eine künstliche Ernährung bei Menschen mit fortgeschrittener Demenz als Entscheidung am Lebensende und zeichnen ein deutliches Bild ihres Leitmotivs einer gelingenden Sterbebegleitung, die sie "würdevoll" und nach dem Willen des Patienten ermöglichen wollen.

> *"Ich finde es immer gut, wenn der Mensch, wenn dieses Sterben nicht ausgelagert ist, sondern im häuslichen Umfeld so ruhig und so harmonisch wie möglich stattfindet, ohne störende Eingriffe, ohne irgendwelche Fürchterlichkeiten. So, dass man sagen kann, der Sterbende führt Regie. Das wäre mir ein Anliegen. Und dass man dann natürlich auch die Voraussetzungen dafür schafft, das möglich zu machen. Beispielsweise wie heute diese Palliative-Care-Teams, und mit einer vernünftigen Schmerztherapie. Das muss sein."* (P12)

6 ZUSAMMENFASSUNG

Wer die Haushoheit in den verschiedenen Settings hat, besitzt gleichzeitig die maßgebliche Entscheidungsgewalt. So treffen im Akutkrankenhaus den Mediziner die Entscheidungen über eine künstliche Ernährung bei Menschen mit Demenz und schließen die Pflegenden weitgehend aus. Im Altenheim dagegen okkupieren die Pflegenden bei solchen Entscheidungen den größten Entscheidungs -und Handlungsspielraum. In der ambulanten Pflege stehen die Pflegenden an der Seite der Angehörigen und ermächtigen diese zu einer Entscheidung im Sinne der Patienten und gemäß ihrer pflegerischen Intention einer "würdevollen Sterbebegleitung". Bei aller Unterschiedlichkeit der pflegerischen Teilhabe in solchen Entscheidungsfindungsprozessen in den verschiedenen Setting engagieren die Pflegenden sich in allen Settings dafür, dass der Wille des Patienten die Entscheidung leitet. Deshalb ist es eine weiterführende Forschungsaufgabe, die Rollengestaltung der Pflegenden tiefer gehend zu betrachten. Insbesondere sollte es darum gehen, ihre Formen der Interpretation des Patientenwillens aufzudecken und zu analysieren. Was tun die Pflegenden, um diesen interpretierten Willen um- bzw. durchzusetzten und was unterlassen sie? Inwieweit entspricht der von ihnen festgestellte Wille den tatsächlichen Vorstellungen des dementen Patienten? Ist es eher die eigene Vorstellung der Pflegenden von einer würdevollen Pflege am Lebensende, die sie leitet? Viele Pflegende benennen es als großes Anliegen ihre Patienten am Lebensende bestmöglich zu pflegen und zu begleiten. Sie besitzen sehr konkrete Vorstellungen darüber, wie sie diese Pflege gestaltet wollen. Es sind jedoch ihre persönlichen Vorstellungen von einem guten Sterben, die sie mit "in Frieden sterben", "zuhause sterben", "nach seinen Wünschen" und "im Kreis seiner Lieben" beschreiben. Ob diese Wünsche auch die der Patienten sind, bleibt in vielen Fällen offen.

Es entsteht der Eindruck, als wollten die Pflegenden mit "ihrer Pflege am Lebensende" für sich ein originäres pflegerisches Handlungs- und

Entscheidungsfeld proklamieren. Scheinbar haben sich Pflegende hier ein anderes Entscheidungsfeld gesucht haben, weil ihnen in vielen Bereichen ein Mitspracherecht bei einer medizinischen Entscheidung verwehrt bleibt oder sie nur indirekt beteiligt werden.

Die weitere vertiefte Analyse der Daten gilt besonders dem pflegerischen Handeln im Entscheidungsfindungsprozess. Die zukünftig noch zu gewinnenden Erkenntnisse der Gesamtstudie können dann mit bereits gewonnenen Erkenntnissen an die Forschungsfragen rückgebunden werden und ein komplexes Bild von Entscheidungsfindungsprozessen über eine künstliche Ernährung am Lebensende bei Menschen mit Demenz zeichnen sowie die Frage nach der Rolle der Pflegenden in Verbindung mit Fragen der Macht beantworten.

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THEORY BASED DEVELOPMENT OF INDICATORS AS THE FOUNDATION OF AN ACTIVE DESIGN OF DEMOGRAPHIC CHANGE IN RURAL AREAS

THEORIEBASIERTE INDIKATORENBILDUNG ALS GRUNDLAGE FÜR EINE AKTIVE GESTALTUNG DES DEMOGRAPHISCHEN WANDELS IN LÄNDLICHEN GEBIETEN

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ABSTRACT

Background: To have a positive influence on the demographic change in rural areas, it is unsatisfactory to focus only on the expected demand for care. Instead of this, the aim of scientific and political intentions has to be an increasing Individual potential, an increasing rate of healthy years and a rising quality of life by active ageing. To support an active ageing in local settings it is necessary to identify indicators that describe the local situation with regard to active ageing.

Method: Based on a detailed search for literature the "Active Ageing" Concept of the World Health Organization 2002 served as theoretical background. This concept describes all relevant aspects of ageing in eight determinants. In order to generate indicators, based on the "Active Ageing" Concept, an operationalization model was developed. The model includes four steps: specification of concept, selection of indicators, rules of correspondence and final specification. In this work, four of the eight dimensions were selected for the operationalization process.

Results: By operationalization the four dimensions "health and social service", "gender", "personal determinants" and "physical environment" a total of 38 indicators were found. The majority of the indicators were generated and specified by definition. The indicators describe the potential local demand as well as the existing resources for an active ageing. Furthermore, the possibility of calculating prospective demographic changes in small scales was included in the indicator system.

Conclusion: Based on this indicator system it is able to identify potential needs for action. It will be possible to define goals, start projects and evaluate those. After a critical discussion, the results of this work could be the starting point for further research and a basis for political decisions. Hence, the indicator system can support the efforts for an active design of demographic change in European rural areas.

KEYWORDS

active ageing, demographical changes, indicator system, rural areas

ZUSAMMENFASSUNG

Hintergrund: Um die Auswirkungen demographischer Entwicklungen in den ländlichen Gebieten Europas günstig zu beeinflussen, ist eine Sichtweise, die sich ausschließlich auf die Sicherstellung des zu erwartenden Versorgungsbedarfes beschränkt, nicht ausreichend. Vielmehr muss das Ziel wissenschaftlicher und politischer Bestrebungen eine Steigerung des individuellen Potentials, der gesunden Lebensjahre sowie der Lebensqualität durch ein aktives Altern sein. Um dieses Ziel auch auf regionaler Ebene umsetzen zu können, ist die dortige Ausgangssituation von zentraler Bedeutung. Dementsprechend wurde in dieser Arbeit die Frage nach Indikatoren zur deskriptiven Beschreibung ländlicher Gebiete in Hinblick auf ein aktives Alterns bearbeitet.

Methode: Basierend auf einer ausführlichen Literaturrecherche wurde das "Active Ageing" Konzept der Weltgesundheitsorganisation aus dem Jahr 2002 als theoretische Grundlage der Indikatorenbildung ausgewählt. Es beschreibt in acht Dimensionen alle den Alterungsprozess beeinflussenden Faktoren. Um diese Faktoren in empirisch messbare Sachverhalte zu übersetzen, wurde ein Operationalisierungsmodell passend zur Fragestellung entwickelt. Das Modell umfasst die vier Schritte Konzeptspezifikation, Auswahl der Indikatoren, Bildung von Korrespondenzregeln sowie die Konkretisierung. Im Rahmen der Arbeit wurden vier der acht Dimensionen operationalisiert.

Ergebnisse: Aus den Dimensionen "Gesundheit und soziale Sicherheit", "physische Umgebung", "persönlichkeitsabhängige Faktoren" sowie dem "Geschlecht" konnten insgesamt 38 Indikatoren operationalisiert und beschrieben werden. Die größtenteils definitorisch entwickelten Indikatoren bilden sowohl potentiellen Bedarf als auch bestehende Ressourcen ab. Darüber hinaus wurde die Möglichkeit Demographie bedingte Veränderungen in unterschiedlichen Bereichen kleinräumig abzubilden und prospektiv zu berechnen als Indikator einbezogen.

Diskussion & Schlussfolgerung: Die Überführung des "Active Ageing" Modells in empirisch messbare Sachverhalte ermöglicht es die unterschiedlichen Voraussetzungen und Einflussfaktoren für ein aktives Altern auf lokaler Ebene abzubilden und Handlungsbedarf zu identifizieren. Entsprechend können Ziele benannt, Maßnahmen eingeleitet sowie deren Effektivität bewertet werden. Im Anschluss an deren kritische Diskussion bietet der entwickelte Indikatorensatz einen empirischen Ausgangspunkt für politische Entscheidungen und zukünftige Forschungsvorhaben und leistet so einen wichtigen Beitrag zur aktiven Gestaltung des demographischen Wandels in Europa.

SCHLÜSSELWORTE

Aktives Altern, demographischer Wandel, Indikatorensatz, ländlicher Raum

1 EINLEITUNG

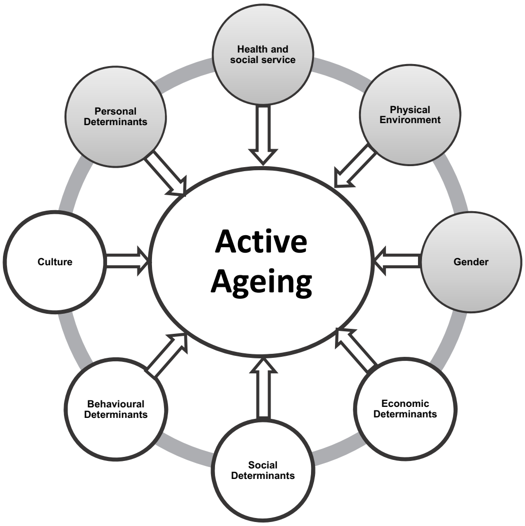
Der demographische Wandel in Europa führt zu einem stetig wachsenden Versorgungsbedarf der Bevölkerung. Aufgrund der überdurchschnittlich hohen Alterung sowie einer schlechten Versorgungsstruktur ist die Bevölkerung in ländlichen Gebieten besonders durch eine potentielle Unterversorgung gefährdet und somit als Forschungsgegenstand von besonderer Relevanz. Um dieser Problematik entgegenzuwirken, ist eine Sichtweise, die sich ausschließlich auf die Sicherstellung des zu erwartenden Versorgungsbedarfes beschränkt, nicht ausreichend und reduziert den Prozess des Alterns auf ein rein negatives Ereignis, dessen Folgen eine Belastung für die Gesellschaft darstellen. Vielmehr muss das Ziel wissenschaftlicher und politischer Bestrebungen eine Steigerung des individuellen Potentials, der gesunden Lebensjahre sowie der Lebensqualität durch ein aktives Altern und somit eine Reduzierung von Versorgungsbedarf sein. Da der Prozess des Alterns dort stattfindet und dort beeinflusst werden kann wo Menschen leben, ist die lokale Situation Ausgangspunkt für alle Bestrebungen, die ein aktives Altern zum Ziel haben.

1.1 Hintergrund

Die Gründe für die überdurchschnittliche Alterung in den ländlichen Gebieten Deutschlands sind die Abwanderung junger Menschen in urban geprägte Gebiete bei einer gleichzeitigen Zuwanderung von Menschen in der Erwerbsaustrittsphase. Verschärft wird diese Situation durch einen überproportional hohen Rückgang der Geburtenrate sowie einen in den 1960er Jahren stattgefundenen Zuzug von Familien in ländliche Gebiete (Beetz, 2009, 117). Dieser hohe Anteil älterer Menschen in ländlichen Gebieten führt auch zu einem erhöhten Versorgungsbedarf, da mit steigendem Lebensalter sowohl die Morbidität (Saß *et al.,* 2009, 31) als auch die Pflegebedürftigkeit (Statistisches Bundesamt, 2011, 8) deutlich zunimmt und die individuelle Mobilität abnimmt. Diesem Bedarf steht eine unzureichende Versorgungsstruktur für ältere Menschen in den ländlichen Gebieten gegenüber. Demnach gilt, je kleiner die Gemeinde und geringer die Zentralität, desto geringer ist auch die Dichte der zur Verfügung stehenden Versorgungsleistungen. Dieser Mangel an Angeboten führt zu einer schlechteren Versorgung und somit zu einem schlechteren Gesundheitszustand der Bevölkerung (Walter und Schwartz, 2000, 84). Zusätzlich zur geringen Zahl an Angeboten gefährden eine schlechte Infrastruktur (Walter und Schwartz 2000, 84), erhebliche Entfernungen zu relevanten Versorgungsangeboten (Beetz, 2009, 126), lange Wege zu öffentlichen Verkehrsmitteln, eine häufig nicht vorhandene Barrierefreiheit (BMFSFJ, 2005, 241/242) sowie eine schlechte Anbindung an Oberzentren (Habich und Spellerberg, 2008, 324) die Lage in ländlichen Gebieten. Dies wirkt sich hauptsächlich auf die medizinische und pflegerische Versorgung der Bevölkerung aus (Walter und Schwartz, 2000, 85/86). Zudem ist die besonders relevante hausärztliche Versorgung aufgrund schlechter Arbeitsvoraussetzungen in den ländlichen Regionen nach wie vor rückläufig (Beetz, 2009, 126). Durch die Abwanderung junger Menschen in wirtschaftlich attraktive Gebiete (BMFSFJ, 2005, 302) kommt es zusätzlich zu einer Abnahme von potentieller familiärer Unterstützung. Somit führt die schnell alternde Gesellschaft im ländlichen Raum zu einer zunehmenden Überlastung des öffentlichen Dienstleistungssektors (OECD, 2007, 191). Um dieser Problematik entgegenzuwirken und das Gleichgewicht zwischen Angebot und Bedarf wieder herzustellen, bestehen die beiden grundsätzlichen Möglichkeiten das Angebot zu erhöhen oder den Bedarf zu senken. Die Angebotssteigerung ließe sich dabei sowohl durch die quantitative Erhöhung der Leistungen als auch durch eine Optimierung der bereits bestehenden Angebote erreichen (Marckmann, 2007, 98/99 sowie Mardorf und Böhm, 2009, 279). Eine solche Anpassung des Angebotes an die demographischen Veränderungen würde zwar die Versorgung älterer Menschen im ländlichen Raum sicherstellen, wäre allerdings mit einer erheblichen Belastung des Systems verbunden. Darüber hinaus beachtet eine solche krankheitsorientierte Herangehensweise an die Problematik den Prozess des Alterns als rein negatives Ereignis. Eine solche Sichtweise ist nicht zeitgemäß und lässt das Recht alter Menschen auf Teilhabe und Selbstbestimmung ebenso außer Acht wie deren Potentiale (Walker, 2010, 587). Die zweite Möglichkeit die zukünftige Versorgung sicherzustellen, ist die Senkung des Bedarfs an Versorgungsleistungen. Eine solche Bedarfssenkung ist indirekt über die Kürzung der finanzierten Leistungen möglich. Hierbei ändert sich allerdings nicht der tatsächliche Bedarf, sondern die Definition von dem, was als Bedarf anerkannt und somit finanziert wird (Marckmann, 2008, 891 / 892). Eine andere, in der öffentlichen Diskussion häufig vernachlässigte Möglichkeit der Bedarfssenkung ist die Steigerung an gesunden Lebensjahren (Mardorf und Böhm, 2009, 290). Berechnungen der EU Kommission zufolge ließe sich der zu erwartende Ausgabenanstieg halbieren, sollte es gelingen die Menschen bei steigender Lebenserwartung länger gesund zu erhalten (Kommission der Europäischen Gemeinschaften, 2007, 8/9). Die Europäische Kommission sieht dabei den Verbleib älterer Menschen im Erwerbsleben, den Erhalt von Gesundheit sowie die aktive Teilhabe älterer Menschen am sozialen Leben als zentrale Aspekte, um den Belastungen des demographischen Wandels zu begegnen (European Commission, 2010, 1/2). Diese auf Gesundheit und aktive Teilhabe ausgelegte Sichtweise umfasst Maßnahmen, welche die Gesundheit der Bevölkerung im gesamten Lebensverlauf fördern (Kommission der Europäischen Gemeinschaften, 2007, 9). Sie beinhaltet somit weit mehr als die rein kurative Behandlung von Krankheiten und die Sicherstellung von Pflege. Die Weltgesundheitsorganisation bezeichnet diese umfassende Sichtweise auf den Prozess des Alterns als „Active Ageing“ und beschreibt diese im Rahmen eines Konzeptes anhand von acht zentralen Determinanten (Abbildung 1). Demnach soll allen Menschen die Möglichkeit gegeben werden

"…ihr Potenzial für körperliches, soziales und geistiges Wohlbefinden im Verlaufe ihres gesamten Lebens auszuschöpfen und am sozialen Leben in Übereinstimmung mit ihren Bedürfnissen, Wünschen und Fähigkeiten teilzunehmen; gleichzeitig soll für Hilfsbedürftige ausreichender Schutz, Sicherheit und Pflege gewährleistet sein." (WHO, 2002b, 12).

Abbildung 1. Das Active Ageing Konzept



Das Konzept des „Aktiven Alterns" betrachtet den Prozess des Alterns als individuelles Ereignis im Kontext seiner Umgebung, welches alle Lebensbereiche der Menschen umfasst. Dem liegt die Erkenntnis zu Grunde, dass Gesundheit dort entsteht, wo Menschen leben und altern (WHO, 2002a, 12).

1.2 Zielsetzung & Fragestellung

Um ein aktives Altern zu ermöglichen, sind Maßnahmen notwendig, welche die Menschen vor Ort dabei unterstützen ihr Gesundheitspotential effektiv zu nutzen, am gesellschaftlichen Leben teilzuhaben sowie bei Bedarf Unterstützungsleistungen in Anspruch nehmen zu können. Die Voraussetzungen hierfür müssen auf regionaler Ebene geschaffen werden (Altgeld, 2009, 156 und Walke,r 2002, 134). Entsprechend ist die individuelle Ausgangssituation der betroffenen Region die Grundlage für Maßnahmen und Entscheidungen (Meier und Esche, 2006, 7). Gesundheitsprofessionelle als auch politische Entscheidungsträger sind somit auf verlässliche Daten angewiesen, die es ihnen ermöglichen Situationen einzuschätzen, Tendenzen abzusehen, entsprechende Schritte einzuleiten und ergriffene Maßnahmen zu beurteilen (Walter und Schwartz, 2003, 111). Als Grundlage für die Datenerhebung sind aussagekräftige Indikatoren notwendig, die alle relevanten Aspekte eines aktiven Alterns benennen und deren Ausprägung aufzeigen. Solche Indikatoren müssen zielgerichtet ausgewählt werden und orientieren sich idealerweise an übergeordneten Theorien oder Programmen (Osius *et al.,* 2001, 3). Ziel dieser Arbeit ist es demnach, Indikatoren zu benennen und darzustellen, die eine deskriptive Beschreibung ländlicher Gebiete im Hinblick auf ein aktives Altern ermöglichen.

Den Annahmen folgend, dass demographische Veränderungen in ländlichen Gebieten durch die Möglichkeit aktiv zu altern positiv beeinflusst werden können und dass die Voraussetzungen für eine erfolgreiche Umsetzung des aktiven Alterns auf regionaler Ebene liegen (Walker, 2002, 134) wurde in der vorliegenden Arbeit folgende Forschungsfrage bearbeitet:

Welche Indikatoren sind zur Beschreibung des ländlichen Raums im Hinblick auf die Anforderungen eines aktiven Alterns geeignet?

Die identifizierten Indikatoren dienen als Grundlage für die Beschreibung von Ressourcen und Handlungsbedarf bezogen auf ein aktives Altern. Sie ermöglichen die Definition von Zielen, die Benennung von Handlungsschritten sowie die Evaluation von Maßnahmen.

2 METHODE

Zur Bearbeitung der Fragestellung wurde in einem ersten Schritt eine ausführliche und systematische Literaturrecherche zum Thema aktives Altern und ländlicher Raum durchgeführt. Neben einer freien Recherche unterschiedlichster Literatur in Bibliotheken und im Internet wurde auch eine systematische Literaturrecherche in den elektronischen Datenbanken EMBASE, Pubmed, The Cochrane Library sowie der Datenbank des Deutschen Zentrums für Altersfragen (DZA) durchgeführt. Aufgrund der geplanten Indikatorenbildung wurde zusätzlich zur inhaltlichen Analyse eine Sichtung relevanter methodischer Literatur zur Indikatorenbildung durchgeführt. Nach Sichtung und Bewertung der methodischen Literatur wurde der deduktive Prozess der Operationalisierung von Indikatoren aus einem theoretischen Modell der induktiven Benennung von Indikatoren vorgezogen. Im Rahmen der Literaturrecherche konnte das „Active Ageing" Konzept der Weltgesundheitsorganisation aus dem Jahr 2002 als geeigneter theoretischer Hintergrund für die Indikatorenbildung bestätigt werden.

Operationalisierung

Zur Bildung von Indikatoren aus dem Active Ageing Konzept heraus wurde im Rahmen dieser Arbeit in Anlehnung an Babbie, 2007, Schnell *et al.,* 2008, Kromrey, 2009 und Atteslander, 2010 ein Ablaufmodell zur Operationalisierung des Active Ageing Konzeptes entwickelt. Ziel des Operationalisierungsmodells ist es, aus dem bestehenden Konzept heraus schrittweise Indikatoren zu entwickeln und dabei ein gleiches Vorgehen bei allen Dimensionen zu gewährleisten.

Unter Operationalisierung versteht Kromrey 2009 *„…die Verknüpfung von Begriffen mit empirischen Sachverhalten…“* (Kromrey, 2009, 110), so dass mittels Forschungs-operationen festgestellt werden kann, ob und in welcher Ausprägung der empirische Sachverhalt in der Realität vorhanden ist (Kromrey 2009: 110). Zur Operationalisierung des „Active Ageing“ Konzeptes lassen sich die vier wesentlichen Schritte Konzeptspezifikation, Auswahl der Indikatoren, Bildung von Korrespondenzregeln sowie eine Konkretisierung ableiten.

Konzeptspezifikation

Unter Konzeptspezifikation versteht man die rein theoretische Klärung, welche Dimensionen durch das Konzept angesprochen werden (Schnell *et al.,* 2008, 128). Im Rahmen der Konzeptspezifikation sollen somit unscharfe und unpräzise Begriffe spezifiziert und präzisiert werden (Babbie, 2007, 124). Ziel der Konzeptspezifikation ist es, „*die Brücke zwischen der abstrahierenden Theorieperspektive und dem Gegenstandsbereich, auf den sich die Theorie bezieht, zu schlagen.*“ (Kromrey, 2009, 176).

Auswahl der Indikatoren

Im Anschluss an die Benennung der Begriffsdefinitionen erfolgt die Zuweisung empirisch beobachtbarer Sachverhalte zu den theoretischen Vorstellungen (Kromrey, 2009, 176). Diese Zuordnung von beobachtbaren Sachverhalten zu den jeweiligen Begriffsdimensionen darf dabei nicht zufällig erfolgen, sondern muss begründet sein und mittels Korrespondenzregeln nachvollziehbar gemacht werden (Kromrey, 2009, 176).

Korrespondenzregel

Die Korrespondenzregel beschreibt in Form einer hypothetischen Formulierung den vermuteten oder empirisch bestätigten Zusammenhang, die Korrespondenz, zwischen den im Rahmen der Konzeptspezifikation entwickelten theoretischen Dimensionen und dem beobachtbaren Sachverhalt (Indikator), der diese widerspiegeln soll. Korrespondenzregeln können durch Theorien, empirische Einzelbefunde oder Definitionen (Zuordungsdefinition) begründet sein (Kromrey, 2009, 181). Das Active Ageing Konzept selbst gibt einen Entwurf für die Bildung von Korrespondenzregeln vor (Friedrichs, 1990, 81). Die Formulierung von Korrespondenzregeln orientiert sich bei definitorischen Indikatoren sehr nahe an den Begriffsdimensionen des Konzeptes (Kromrey, 2009, 163/174).

Konkretisierung

Der letzte Schritt der Operationalisierung ist die Konkretisierung. Diese erfolgt durch die Angabe des Skalenniveaus, des Differenzierungsgrades, der Messvorschriften sowie der möglichen Analyseeinheit. Zusätzlich sollen, falls vorhanden, Vergleichswerte angegeben werden, um eine Einordnung ländlicher Gebiete anhand der Indikatorenausprägung zu ermöglichen (Tabelle 1). Diese Konkretisierung erleichtert eine spätere Entwicklung eines Erhebungsinstruments sowie die statistische Auswertung der Daten. Durch diese Differenzierungen werden die gebildeten Indikatoren im statistischen Sinne zu Variablen und ermöglichen im Rahmen der Datenauswertung eine Beschreibung der empirischen Sachverhalte anhand deren Ausprägung (Kromrey, 2009, 192).

Tabelle 1. Darstellung der Indikatoren

Indikator	= Definition
Anzeiger für	Welchem theoretischen Begriff ist der messbare empirische Sachverhalt zuzuordnen
Korrespondenzregel	(Hypothetischer) Zusammenhang zwischen benanntem Indikator und dem zu messenden Sachverhalt und dessen Zusammenhang mit dem aktiven Altern
Skalenniveau	Angabe des Skalenniveaus: nominal, ordinal, intervall, verhältnis
Differenzierungsgrad Messvorschrift & Vergleichswert	Festlegung des Differenzierungsgrades und der Messvorschrift (Messeinheit)
Analyseeinheit	Festlegung möglicher Datenquellen: Beobachtung – Befragung – Datenanalyse

3 ERGEBNISSE

Im Rahmen der vorliegenden Arbeit wurden vier der acht Determinanten des Active Ageing Konzeptes zur Operationalisierung ausgewählt. Aus den Determinanten „Gesundheit und soziale Sicherheit“, „physische Umgebung“, „persönlichkeits-abhängige Faktoren“ sowie „Geschlecht“ konnten 10 Determinanten mit insgesamt 16 Aspekten operationalisiert und beschrieben werden. Diese lassen sich mit Hilfe von 38 Indikatoren an der empirischen Wirklichkeit abbilden. Basierend auf der Fragestellung konnten zusätzlich zwei Indikatoren zur Beschreibung der Bevölkerung identifiziert werden. Um die einzelnen Aspekte mit Hilfe von empirisch messbaren Sachverhalten abzubilden, wurden die möglichen Indikatoren mittels Definition bestimmt und deren Korrespondenz zur theoretischen Dimension beschrieben. Im Anschluss an die Diskussion der jeweiligen Vor- und Nachteile wurden die geeignetsten Indikatoren ausgewählt, konkretisiert und in das Indikatorsystem überführt. Wichtig hierbei war es, dass die gewählten Indikatoren sowohl empirisch praktikabel als auch theoretisch sinnvoll sind (Atteslander, 2010, 41). Nachfolgend werden die jeweilig ausgewählten Indikatoren in ihrem Zusammenhang zu den Aspekten, Dimensionen und Determinanten benannt und dargestellt.

Gesundheit und soziale Sicherheit

Aus der Determinante Gesundheit und soziale Sicherheit konnten die vier zentralen Dimensionen „Gesundheitszustand“, „Prävention & Gesundheitsförderung“, „medizinische Versorgung“ sowie die „pflegerische Versorgung“ operationalisiert werden.

Gesundheitszustand

Die Dimension des Gesundheitszustandes umfasst den einen konkretisierenden Aspekt „Gesundheitszustand der Bevölkerung“. Dieser kann über die klassischen und weltweit anerkannten Maßzahlen Morbidität und Mortalität abgebildet werden. Eine weitere wichtige Möglichkeit zur Einschätzung des Gesundheitszustandes der Bevölkerung ist die so genannte „subjektive Gesundheit“. Diese spiegelt neben den objektiven Einschränkungen auch die persönliche, soziale und gesellschaftliche Dimension von Gesundheit wider (Tabelle 2).

Tabelle 2. Dimension Gesundheitszustand

Dimension	Aspekt	Indikator
Gesundheitszustand	**Gesundheitszustand der Bevölkerung**	Morbidität
		Mortalität
		Subjektive Gesundheit

Prävention und Gesundheitsförderung

Innerhalb der Dimension Prävention und Gesundheitsförderung lassen sich die beiden Aspekte „Primärprävention und Gesundheitsförderung“ sowie die „Sekundärprävention“ mittels Operationalisierung bestimmen. Die Sekundärprävention wird dabei über die „Inanspruchnahme von Früherkennungsuntersuchungen“ abgebildet. Die Primärprävention und Gesundheitsförderung wird über die vier Indikatoren „Gesundheitsbezogene Lebensqualität“, „Wahrnehmung der eigenen Lebenswelt hinsichtlich Gesundheit“, den „eigenen Möglichkeiten die Gesundheit zu beeinflussen“ und den „eigenen Fähigkeiten die Lebensumgebung zu beeinflussen“ abgebildet (Tabelle 3).

Tabelle 3. Dimension Prävention und Gesundheitsförderung

Dimension	Aspekte	Indikator
Prävention & Gesundheitsförderung	**Primärprävention & Gesundheitsförderung**	Gesundheitsbezogene Lebensqualität
		Wahrnehmung der eigenen Lebenswelt hinsichtlich Gesundheit
		Eigene Möglichkeit die Gesundheit zu beeinflussen
		Eigene Fähigkeit die Lebensumgebung zu beeinflussen
	Sekundärprävention	Inanspruchnahme von Früherkennungsuntersuchungen

Medizinische Versorgung

Die dritte Dimension der Determinante Gesundheit und soziale Sicherheit ist die medizinische Versorgung der Bevölkerung. Diese besteht aus den Aspekten „medizinische Versorgung“ und „Rehabilitation“. Die medizinische Versorgung wird mittels der Indikatoren „Verhältnis Arzt zu Einwohner“ und „Verhältnis Krankenhausbetten zu Einwohner“ abgebildet. Die Rehabilitation kann über das „Verhältnis Betten in Vorsorge - und Rehabilitationseinrichtungen zu Einwohner“ sowie über das Vorhandensein von für die Rehabilitation notwendigen Angeboten innerhalb eines Strukturraumes“ erhoben werden (Tabelle 4).

Tabelle 4. Dimension Medizinische Versorgung

Dimension	Aspekte	Indikator
Medizinische Versorgung	**Medizinische Versorgung**	Verhältnis Arzt zu Einwohner
		Verhältnis Krankenhausbetten zu Einwohner
	Rehabilitation	Verhältnis Betten in Vorsorge – und Rehabilitationseinrichtungen zu Einwohner
		Vorhandensein von für die Rehabilitation notwendigen Angeboten innerhalb eines Strukturraumes

Pflegerische Versorgung

Die pflegerische Versorgung im Rahmen des Active Ageing Konzeptes umfasst die beiden Aspekte „professionelle pflegerische Versorgung“ und „informelle Hilfs- und Unterstützungsleistungen“. Hierbei wird die professionelle pflegerische Versorgung innerhalb eines Strukturraums über die „Anzahl der Pflegebedürftigen“, das „Verhältnis stationärer Pflegebetten zu Pflegebedürftigen“, das „Verhältnis ambulanter Pflegekräfte zu Pflegebedürftigen“, den „Bedarf an palliativer und hospizlicher Versorgung“ sowie die „Kapazität an palliativen und hospizlichen Versorgungsangeboten“ abgebildet. Die Indikatoren für die informellen Hilfs – und Unterstützungsleitungen sind einerseits der „Bedarf an Hilfs – und Unterstützungsleitungen außerhalb des SGB XI“ sowie die „Inanspruchnahme von Hilfs- und Unterstützungsleistungen, die durch Angehörige oder Dritte erbracht werden“. Andererseits wurden "Alters- und krankheitsbedingte Einschränkungen“, "Einschränkungen in unterschiedlichen Lebensbereichen“ sowie die „Bereitschaft Hilfs- und Unterstützungsleistungen innerhalb der Gemeinde zu erbringen“ als wichtige Indikatoren identifiziert (Tabelle 5).

Tabelle 5. Dimension Pflegerische Versorgung

Dimension	Aspekte	Indikator
Pflegerische Versorgung	**Professionelle pflegerische Versorgung**	Anzahl Pflegebedürftiger (SGB XI)
		Verhältnis stationärer Pflegebetten zu Pflegebedürftigen
		Verhältnis ambulanter Pflegekräfte zu Pflegebedürftigen
		Bedarf an palliativer und hospizlicher Versorgung
		Kapazität palliativer und hospizlicher Versorgungsangebote
	Informelle Hilfs– und Unterstützungs-leistungen	Bedarf an Hilfs – und Unterstützungsleistungen außerhalb SGB XI
		Inanspruchnahme von Hilfs- und Unterstützungsleistungen, die durch Angehörige oder Dritte erbrachte werden
		Alters- und krankheitsbedingte Einschränkungen
		Einschränkungen in unterschiedlichen Lebensbereichen
		Bereitschaft Hilfs- und Unterstützungsleistungen innerhalb der Gemeinde zu erbringen

Physische Umgebung

Die zweite im Rahmen dieser Arbeit operationalisierte Determinante ist die der physischen Umgebung. Diese wurde durch die Operationalisierung in die drei Dimensionen „Sicherheit“, „Erreichbarkeit“ sowie „situationsgerechte Wohnung“ unterteilt.

Sicherheit

Die Dimension der Sicherheit im Active Ageing Konzept umfasst den Aspekt der Unfallgefährdung. Diese wird über die „wahrgenommenen Gefahrenstellen innerhalb der eigenen Wohnung“, die „wahrgenommenen Gefahrenstellen in der Wohnumgebung“ sowie die „funktionalen Einschränkungen & Einschränkungen in der Sehfähigkeit“ konkretisiert (Tabelle 6).

Tabelle 6. Dimension Sicherheit

Dimension	Aspekt	Indikator
Sicherheit	**Unfallgefährdung**	Wahrgenommene Gefahrenstellen innerhalb der eigenen Wohnung
		Wahrgenommene Gefahrenstellen in der Wohnumgebung
		Funktionale Einschränkungen & Einschränkungen in der Sehfähigkeit

Erreichbarkeit

Die Erreichbarkeit ist ebenfalls ein wichtiger Bestandteil der physischen Umgebung und kann im Rahmen der Operationalisierung in die drei Aspekte „räumliche Nähe“, „Mobilität“ sowie „Barrierefreiheit“ unterteilt werden. Die räumliche Nähe wird hierbei über die „Entfernung zu Dienstleistern und zentralen Orten“ sowie über die „Entfernung zu Verwandten“ abgebildet. Die Indikatoren zur Beschreibung der Mobilität sind zum einen die „unterschiedlichen Möglichkeiten sich fortzubewegen“ und zum anderen die „Qualität (Verfügbarkeit & Taktung) öffentlicher Verkehrsmittel“. Der Aspekt der Barrierefreiheit wird anhand der „Mobilitätseinschränkungen aufgrund von Barrieren“ dargestellt (Tabelle 7).

Tabelle 7. Dimension Erreichbarkeit

Dimension	Aspekte	Indikator
Erreichbarkeit	**Räumliche Nähe**	Entfernung zu Dienstleistern und zentralen Orten
		Entfernung zu Verwandten
	Mobilität	Unterschiedliche Möglichkeit sich fortzubewegen
		Qualität (Verfügbarkeit & Taktung) öffentlicher Verkehrsmittel
	Barrierefreiheit	Mobilitätseinschränkungen aufgrund von Barrieren

Situationsgerechte Wohnung

Die Dimension der Situationsgerechten Wohnung kann anhand der „Erfüllung der Wohnbedürfnisse“ beschrieben werden. Diese umfasst die vier Indikatoren „Subjektive Zufriedenheit mit der Wohnsituation“, „Adäquate Nutzung der Wohnung“, „Notwendige oder bereits durchgeführte Anpassungsmaßnahmen“ sowie „das Vorhandensein & die Inanspruchnahme technischer Geräte“ (Tabelle 8).

Tabelle 8. Dimension Situationsgerechte Wohnung

Dimension	Aspekt	Indikator
Situations-gerechte Wohnung	**Erfüllung der Wohnbedürfnisse**	Subjektive Zufriedenheit mit der Wohnsituation
		Adäquate Nutzung der Wohnung
		Notwendige oder bereits durchgeführte Anpassungsmaßnahmen
		Vorhandensein & Inanspruchnahme technischer Geräte

Persönliche Einflüsse

Die Determinante „persönliche Einflüsse“ im Active Ageing Konzept umfasst die beiden Dimensionen „Biologie und Genetik“ sowie die „psychologischen Faktoren“.

Biologie und Genetik

Die Dimension Biologie und Genetik beinhaltet den Aspekt „genetische Voraussetzungen für die Entstehung von Krankheit“, der über „in der Familie bekannte (Erb-) Krankheiten“ messbar gemacht werden kann (Tabelle 9).

Tabelle 9. Dimension Biologie und Genetik

Dimension	Aspekte	Indikator
Biologie und Genetik	**Genetische Voraussetzungen für die Entstehung von Krankheit**	In der Familie bekannte (Erb-) Krankheiten

Psychologische Faktoren

Die Dimension der psychologischen Faktoren im Active Ageing Konzept wird einerseits über die „kognitiven Fähigkeiten“ abgebildet und mittels der „Ausprägung von Verhaltensweisen, die für die kognitive Leistungsfähigkeit relevant sind“ messbar gemacht. Andererseits ist die „Selbsteffizienz“ ein wichtiger Aspekt dieser Dimension und wird über die „Self – Efficacy Scale“ erhoben (Tabelle 10).

Tabelle 10. Dimension Psychologische Faktoren

Dimension	Aspekt	Indikator
Psychologische Faktoren	**Kognitive Fähigkeiten**	Ausprägung von Verhaltensweisen, die für die kognitive Leistungsfähigkeit relevant sind
	Die Selbsteffizienz	Self – Efficacy Scale

Geschlecht

Im Rahmen des Active Ageing Konzeptes stellt das Geschlecht, das sowohl Determinante, Dimension, Aspekt und Indikator darstellt eine zentrale Rolle, da es sich auf unterschiedliche Bereiche des aktiven Alterns auswirkt (Tabelle 11).

Tabelle 11. Dimension Geschlecht

Dimension	Aspekt	Indikator
Geschlecht	**Geschlecht**	Geschlecht

Bevölkerung

Bezogen auf die zugrundeliegende Fragestellung konnten zwei zusätzliche, außerhalb des Active Ageing Konzeptes liegende Aspekte benannt werden, die einer Beschreibung der Bevölkerung als Grundlage für eine Einschätzung des Erhebungsgebietes dienten. Demnach konnten die „Bevölkerung nach Alter“ sowie die Möglichkeit „Demographie bedingte Veränderungen“ mittels des Status Quo Modells messbar zu machen als zusätzliche Indikatoren benannt werden (Tabelle 12).

Tabelle 12. Zusätzliche Dimension Bevölkerung

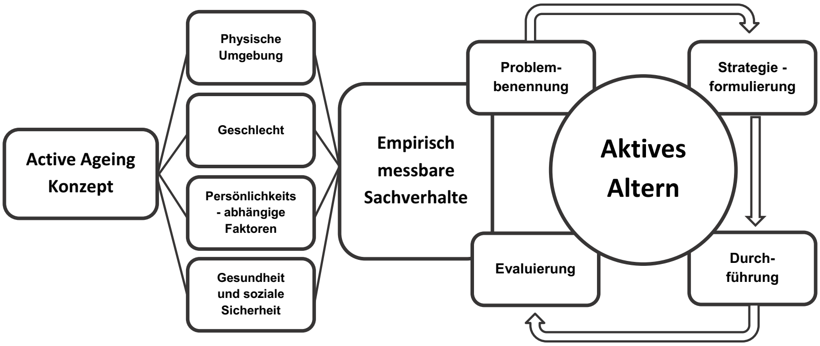
Dimension	Aspekte	Indikator
Bevölkerung	**Bevölkerung nach Alter**	Altersspezifische Darstellung der Bevölkerung
	Demograpie-bedingte Veränderungen	Demographiebedingte Veränderungen, berechnet anhand des Status Quo Modells

4 DISKUSSION UND SCHLUSSFOLGERUNG

Durch die Überführung des theoretischen Konzeptes in empirisch messbare Indikatoren wird eine Darstellung ländlicher Gebiete im Hinblick auf die Anforderungen des aktiven Alterns möglich. Mit Hilfe des entwickelten Indikatorenkatalogs können vier der acht Determinanten des Konzeptes abgebildet werden. Anhand der Indikatoren kann festgestellt werden, in welcher Ausprägung ein empirischer Sachverhalt innerhalb des Erhebungsgebietes vorliegt (Kromrey, 2009, 110). Sie ermöglichen somit eine Einschätzung darüber, in welchen Bereichen Defizite und in welchen Bereichen Potentiale bestehen. Die Einbeziehung des Status Quo Modells gestattet es zusätzlich, derzeitige Quoten auf zukünftige demographische Veränderungen zu übertragen. Somit kann mittels der Indikatoren sowohl aktueller als auch zukünftiger Handlungsbedarf identifiziert werden. Da das Status Quo Modell von konstanten Quoten ausgeht, ist zu beachten, dass mögliche Veränderungen wie beispielsweise eine Neudefinition der Pflegebedürftigkeit und die sich daraus verändernden Quoten unberücksichtigt bleiben (Statistische Ämter des Bundes und der Länder, 2010, 12 - 27). Während der Operationalisierung von wissenschaftlich noch nicht abschließend begründeten Sachverhalten, wie beispielsweise dem Effekt unspezifischer gesundheitsförderlicher Maßnahmen, kann die Korrespondenz zwischen theoretischem Aspekt und Indikator nur mit hoher Wahrscheinlichkeit angenommen und nicht empirisch überprüft werden (Kromrey, 2009, 163 - 166). Einige Aspekte müssen über mehrere Indikatoren dargestellt werden. Auch können die empirischen Sachverhalte, wie die eigenen Ressourcen älterer Menschen, nur indirekt benannt und abgebildet werden. Die Verknüpfung der Merkmalsausprägungen mit Referenzwerten bereits bestehender Forschungsergebnisse ermöglicht zusätzlich eine Einordnung und Vergleichbarkeit des Strukturraumes mit anderen Gebieten (AOLG, 2003, 13). Hierbei ist zu beachten, dass diese Referenzwerte teilweise unter abweichenden Fragestellungen und anderen Rahmenbedingungen erhoben wurden und daher nicht unreflektiert auf jeden Strukturraum übertragen werden können. Manche Indikatoren, wie die Morbidität, sind bei Bedarf inhaltlich noch weiter ausdifferenzierbar. Darüber hinaus können einzelne Indikatoren auch in anderen Erhebungen Anwendung finden. Grundvoraussetzung hierfür ist allerdings die bestehende Korrespondenz zwischen dem Indikator und dem abzubildenden Sachverhalt in dieser Untersuchung (Kromrey, 2009, 181). Auch ist es denkbar, das „Active Ageing“ Konzept mit Hilfe der Indikatoren auf seinen empirischen Wahrheitsgehalt hin zu überprüfen (Kromrey, 2009, 45). Eine weitere Möglichkeit die entwickelten Indikatoren zu nutzen ist der empirische Nachweis, dass mit Hilfe des „Active Ageing“ Ansatzes tatsächlich der Bedarf an Versorgungsleistungen in ländlichen Gebieten reduziert werden kann. Die erarbeiteten Indikatoren können auch zur Qualitätssicherung im Gesundheitswesen herangezogen werden (Waller, 2006, 146). Um den Indikatorensatz erfolgreich anwenden zu können, ist in einem nächsten Schritt die Operationalisierung der vier fehlenden Determinanten notwendig. Zwar wurde die Validität der Indikatoren bereits in der Operationalisierung sichergestellt, dennoch ist eine erneute Überprüfung des fertigen Erhebungsinstrumentes mittels Experten oder so genannter Extremgruppen sinnvoll. Auch ist vor der praktischen Erprobung und Anwendung der Indikatoren in einem Erhebungsinstrument zusätzlich zur Validität die Reliabilität durch einen Retest zu überprüfen (Atteslander, 2010, 228). Gerade die Sicherstellung der Qualität durch die Gütekriterien ist eine zentrale Voraussetzung für die erfolgreiche Anwendung der hier erarbeiteten Indikatoren. Bindet man die Indikatoren und deren Ausprägungen innerhalb eines Strukturraumes in lokale Aktionspläne und Prozesse wie beispielsweise den „Public Health Action Cycle“ ein, können durch die Indikatoren Problembereiche identifiziert und anhand der Ausprägungen klassifiziert werden. Bei gleicher Datenquelle können zusätzlich Zusammenhänge mit anderen empirischen Sachverhalten hergestellt und somit Probleme und Zielgruppen genauer beschrieben werden. Diese Darstellung der Ausprägungen einzelner Aspekte ermöglicht es darüber hinaus realistisch erreichbare Ziele zu formulieren. Anschließend können Maßnahmen zur Realisierung der Ziele partizipativ mit den Bewohnern geplant und umgesetzt werden. Zur inhaltlichen Umsetzung der Maßnahmen kann der Indikatorensatz lediglich Hinweise geben. Diese muss anhand der lokalen Strukturen und Möglichkeiten erfolgen. Zur Evaluation dieser Maßnahmen lassen sich wiederum die gebildeten Indikatoren verwenden (Waller, 2006, 141). Somit ermöglicht der Indikatorenkatalog, eingebunden in einen

Anwendungsprozess, die praktische Umsetzung des aktiven Alterns auf regionaler Ebene (Abbildung 2).

Abbildung 2. Einbindung des Indikatorenkatalogs in den Public Health Action Circle



Trotz der offenen Ausrichtung des Indikatorensatzes auf einen frei definierbaren Strukturraum bietet er besonders kleinen und ländlichen Gemeinden die Möglichkeit, die tatsächliche Situation darzustellen und zielgerichtete Maßnahmen zur aktiven Gestaltung des demographischen Wandels vorzunehmen. Grundlagen hierfür sind die Einbeziehung kleinräumiger Bevölkerungsvorausberechnungen sowie die Möglichkeit einen Großteil der Aspekte von der Bevölkerung direkt zu erfragen. Es muss deutlich werden, dass das Ziel einer zukunftsorientierten Seniorenpolitik nicht alleine die Sicherstellung der Versorgung sein kann. Vielmehr ist es notwendig Strategien zu entwickeln, die es den Menschen ermöglichen gesund und aktiv zu altern. Der hier vorgestellte Indikatorensatz basiert auf dem Active Ageing Konzept der Weltgesundheitsorganisation und dessen positiver Sichtweise auf den Prozess des Alterns. Der Indikatorensatz ermöglicht es, ein abstraktes theoretisches Modell anhand empirisch messbarer Sachverhalte auf lokaler Ebene abzubilden. Er leistet somit einen grundlegenden Beitrag zur aktiven Gestaltung des demographischen Wandels in ländlichen Gebieten.

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WORKPLACE WELLNESS PROGRAM FOR NURSES: A LOGIC MODEL APPROACH

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ABSTRACT

Background: The present situation in the clinical practices in most hospitals in the Philippines presents great challenges and expectations for nurses to accomplish. Working in very busy large hospitals is considered tedious task. Even the most experienced nurses are confronted with complicated assignments that may threaten their wellness. It is in this context that the researcher conducted this study to determine the nurses' rating of the availability of an existing hospital's (a) basic health promotion program for nurses, (b) the nurses' perceptions of administrative support for the existing hospital health promotion program, and (c) the nurses' appraisal of the scope of workplace wellness promotion in hospital units.

Methodology: A descriptive-correlational method was used. The sample was 131 of 194 staff nurses from a large city government managed hospital. A 0.05 level of significance was used for the following null hypotheses: (1) there are no significant relationships between the respondent's rating of the availability of basic health promotion and their appraisal on the scope of workplace wellness promotion; (2) there are no significant relationships between the respondent's perception of administrative support to the existing hospital health promotion program and their appraisal of the extent of workplace wellness promotion. Data were collected using the Workplace Wellness Questionnaire and interviews. Ranking, weighted mean, and Pearson coefficient were used to analyze data.

Results: Hypothesis 1: the respondents rated the availability of basic health promotion at an overall mean of 2.60. Hypothesis 2: With regard to the administrative support, the respondents perceived that administration was generally supportive. Respondents rated administrative support at an overall mean of 2.61. However, they responded that they rarely experienced an optimum level of wellness, with an overall mean of 2.43. Statistical evidence supported that there is an existing relationship between the extent of workplace wellness and the availability of it and support of the administration.

Conclusions: Weak areas in the workplace were prioritized in the wellness program for nurses. Those areas were: physical activity facilities and access to facilities outside of work hours, nutrition education/weight management, written policies and fitness programs, allocated budget, employee participation and health screening.

Recommendations: Since the respondents experienced a low level of wellness, a nurses' workplace wellness program was formulated and proposed.

KEYWORDS

clinical nurses, logic model, wellness, wellness in the workplace, wellness program

1 INTRODUCTION

The researcher, being aware of the working conditions of staff nurses in city government managed hospitals, observed that even the most experienced nurses are confronted with complicated tasks that threatened their wellness. The prevalence of absenteeism is high due to sickness and other problems that are wellness-related. Some nurses complain about their working conditions, and there were those who are dissatisfied with their work as nurses. These observations prompted the researcher to conduct this study. A workplace health promotion program is essential to increasing nurses'health awareness and decreasing cases of absenteeism and sick leaves. The work areas must provide various opportunities for nurses to express themselves creatively when they are on the verge of giving up so that they may have a healthy and productive well-being and disposition that will redirect their overall thinking and actions (Swinford and Webster, 1989). They should be taught to have a way of life oriented toward optimal health and well-being in which the body, mind, and spirit are integrated in order to live more fully within the human and natural community with which wellness is the driving force (Sweeney and Witmer, 1991, in Myers, 2003). All these opportunities can be provided by the work environment with the assumption that there should be congruence in the seven wellness aspects of individuals being nurtured and developed by the workplace. One way to design innovative institutional programs like wellness in the workplace is through the use of program logic model. In its simplest form, this diagrammatic representation analyzes work into four categories or steps: inputs, activities, outputs, and outcomes. Kirkpatrick (2001) contended that these steps represent the logical flow from inputs covering resources such as money, employees, and equipment to work activities, programs or processes, to the immediate outputs of the work that are delivered to customers, to the outcomes or results that are the long-term consequences of delivering such outputs. According to the development guide by the W.K. Kellogg Foundation, the Program Logic Model provides a picture of how an organization does its work according to the theory and assumptions underlying a program. The model can enhance the participatory role and usefulness of evaluation. Also, the model provides direction by emphasizing the ability to identify outcomes and anticipate ways to measure the outcomes. The Program Logic Model is a strong tool for communicating with diverse people. Based on these premises, the researcher conducted the study to determine the clinical nurses' appraisal of the wellness promotion in each ward or unit, and the significant relationships. It was anticipated that results would provide the necessary baseline data for the proposed Wellness in the Workplace Program for the Nurses. The goal is to enable nurses to continue to live up to their ideals of the nursing profession in terms of excellence in service they provide to their clients.

2 LITERATURE REVIEW

Witmer and Sweeney (1992, 140-148) presented a holistic model for wellness and prevention across the lifespan which is based on psychological theory and empirical research on characteristics of healthy persons. Specifically, the authors incorporated cross-disciplinary research and theoretical concepts from a variety of disciplines that supported certain human characteristics as related to health, longevity, and quality of life. Rona (2006, 80-83) stated that wellness is generally used to indicate a healthy balance of the mind, body and spirit that results in an overall feeling of well-being. Shurts and Myers (2003) found positive relationships between healthy life styles and the life tasks in the Wheel of Wellness and Connolly and Myers (2003, 152-160) found positive associations between job satisfaction, mattering and the life tasks. According to Bates (2008, 124-128), Employee Wellness Programs are organized programs designed to support and assist staff members in establishing healthier lifestyles. Wellness Programs can include things like; increasing employee awareness on health topics, providing behavior change initiatives, and/or establishing corporate policies that support health-related goals and objectives. Programs and policies that promote increased physical activity, tobacco use prevention and cessation, and healthy food selection are a few examples. From a management perspective, wellness programs have the potential to decrease absenteeism, reduce medical claims costs, and improve employee productivity, recruitment, and retention. Many employers credit the implementation of institutionalized fitness programs for productivity gains in areas such as reduced errors, improved efficiency, and improved decision making (Sullivan, 2009, 110-115). Another important factor to consider in the preparation of a wellness program is the identification of the signs of workplace stress and burnout. This was disclosed by Cruz (1994) who commented that mood and sleep disturbances, upset stomach and headache, and disturbed relationships with family, friends, colleagues are examples of wellness related problems. The website http://www.fittogethernc.org (2008) instructed that program design options depend on the goals and desired outcomes of the wellness program. If the goal is to help employees change behavior, reduce risk factors, or save healthcare dollars then the wellness program would be designed to accomplish those outcomes and a budget would be necessary to support that design. Amery (2005, 4) conducted a study on the wellness perception among nurses working in selected US hospitals (particularly in Oncology Departments) and found that the respondents perceived themselves well in the 5 dimensions of wellness developed by Myers (2003, 69-85). Jadada (2009, 170-180) suggested that designing a wellness program should start from an understanding of the causes of workplace maladies. Job strain results from the interaction of the worker and the conditions of work. Views differ on the importance of worker characteristics versus working conditions as the primary cause of job stress. The differing viewpoints suggest there are different ways to prevent stress at work. According to one school of thought, differences in individual characteristics such as personality and coping skills are most important in predicting whether certain job conditions will result to disorders - in other words, what is stressful for one person may not be a problem for another.

2.1 The Program Logic Model

The Program Logic Model (W.K. Kellogg Foundation, 2004) is a systematic and visual way to present and share your understanding of the relationships among the resources you have to operate your program, the activities you plan, and the changes or results you hope to achieve. The model presents a picture of how an organization does its work according to the theory and assumptions underlying a program. It can enhance the participatory role and usefulness of evaluation. The model supports identification of outcomes and anticipation of ways to measure outcomes.

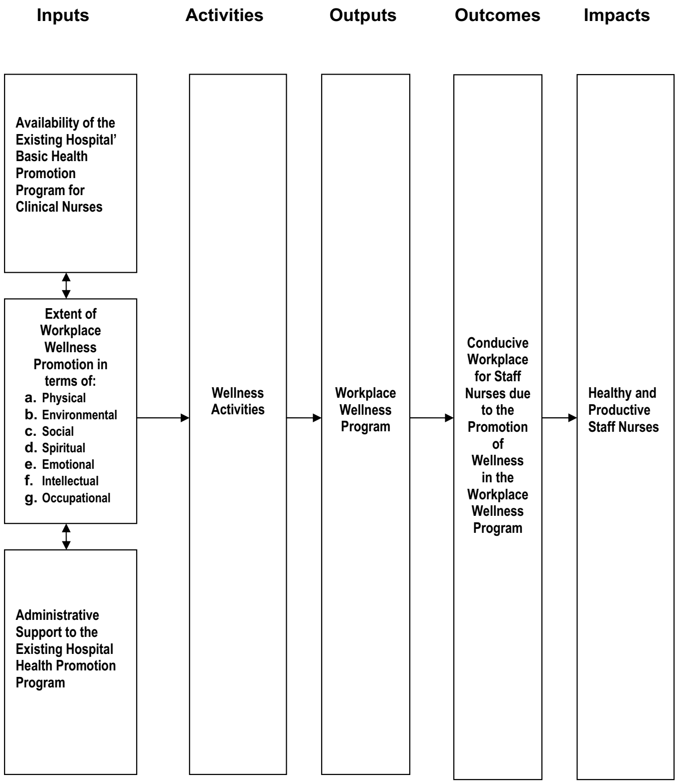
2.1.1 Components of the model

Arrows are used to link the sequence of events necessary for the program to be effective. In addition to the diagram, logic models can include a narrative that explains the relationships between these components. Fully-specified logic models also identify the external factors that can hinder the efforts of program staff or help them achieve the program's objectives. The model may also indicate factors which affect recruiting participants into the program. A well-reasoned logic model draws upon disciplinary knowledge bases to establish the likely outcomes of program activities and factors which can help or hinder a program's success. The logic model components are presented in http://www.uwex.edu/2009. A sequence of actions that describe what the program is and will do and how investments link to results is shown. The five core components in this depiction of the Program Logic Model include:

- INPUTS: resources, contributions, investments that go into the program
- ACTIVITIES: the processes, tools, events, technology, and actions that are an intentional part of the program implementation. These interventions are used to bring about the intended program changes or result
- OUTPUTS: activities, services, events and products that reach people who participate or who are targeted
- OUTCOMES: results or changes for individuals, groups, communities, organizations, communities, or systems
- IMPACTS: the fundamental intended or unintended change occurring in organizations, communities or systems as a result of program activities within 7 to 10 years.

Program Logic Model is a visualization tool that allows depiction of relationships between the components. It places emphasis on unique assumptions and the environment within which a program operates (www.ipmsouth.com, 2012).

Figure 1. Conceptual Paradigm



2.1.2 Factors that can affect the quality of a program

Factors that can affect the quality of a program are: the needs of clientele; content and sequence of activities; availability of resources; and coordination among employees, administrators, and stakeholders. In essence, an effective program gets the right information to appropriate clients in a way that they can understand and apply. One useful tool to help administrators plan an effective program is the logic model. Logic models identify program outcomes, processes in which clients are to engage, and the organization structure for delivering activities. Well-conceived logic models are based on relevant disciplinary research and developed in consultation with users of the developed program (Israel, 2009).

3 RESEARCH METHODOLOGY

This study employed the descriptive-correlational method of research. Zulueta and Costales Jr. (2004) defined this method of research, as a fact-finding study with adequate and accurate interpretation of the findings. This method describes "what is" with emphasis on what actually existed such as current conditions, practices, situations or any phenomena without any control or manipulation of the variables under scrutiny. Since the present study was concerned with the availability of the existing hospital's basic health promotion program for staff nurses, perceived administrative support to the existing hospital health promotion program, extent of workplace wellness promotion in the hospital wards and units and significant relationships between these areas (as rated by the nurse-respondents), the descriptive method of research is the most appropriate method to use. This study was conducted in a 300 bed government administered city hospital in the Phillipines. The hospital is a non-profit tertiary, general and training hospital. As the hospital is operated and is maintained through taxes paid by city residents, its primary concern is the admission and treatment of patients who are bona-fide residents of the city. Furthermore, it is responsible for the provision of an integrated community health program and the promotion of scientific excellence through research activities. This study will support the hospital's goal of excellence in research. The participants in this study were the regular permanent clinical nurses. At present, there are a total of one hundred ninety four (194) regular permanent clinical nurses assigned in the different units of the hospital. The researcher determined the sample size using the Slovin's formula (Ariola, 2006). The researcher utilized the lottery technique, where by all the names of the respondents per unit were placed in separate boxes and these were drawn, until the desired number was achieved. Table 1 shows the breakdown of clinical nurse respondents according to department.

Table 1. Breakdown of Clinical Nurse- Respondents According to Department

Department	Population	Sample Size
A. Special Units	74	50
B. OPD/Infirmary	21	14
C. Medicine	17	12
D. ENT	8	5
E. Pedia	13	9
F. OB/DR	34	23
G. Surgery	19	13
H. Central Supply/Nursing Administration	8	5
Total	194	131

4 FINDINGS AND DISCUSSION

Table 2 presents the composite mean summary of the staff nurses' rating of the availability of the hospital's existing basic health promotion program. Response to cardiac events and emergency is rated at the top of the fourteen areas with the mean of 3.20, followed by written policies on tobacco use and healthcare coverage with respective mean scores of 3.19 and 3.06. The lowest mean score was for physical activity facilities and access to physical activity facilities outside of work hours with the mean of 2.03. These data may mean that, although health promotion is being practiced in the hospital, it seems that not all aspects of a well prepared wellness program are in place, as can be inferred from the responses. It is, however, important to note that cardiac-related incidence emergency handling, prohibition of tobacco use and healthcare coverage are rated high since the workplace is the hospital; and this is the very purpose of their work - to save lives or control sickness.

Table 2. Composite Mean Summary of the Respondents' Rating on the Availability of Existing Hospital's Basic Health Promotion

	Areas Rated	Mean	I	Rank
1.	Worksite Wellness Program Policy and Worksite Wellness Plan	2.62	A	5
2.	Health Committee Representation	2.66	A	4
3.	Written Policies on Physical Activity and Fitness Programs	2.48	PA	12
4.	Breaks or Rest Periods	2.51	A	8
5.	Physical Activity Facilities and Access to Physical Activity Facilities Outside of Work Hours	2.03	PA	14
6.	Written Policies on Nutrition	2.59	A	6
7.	Written Policies on Tobacco Use	3.19	A	2
8.	Response to Cardiac Events and Emergency	3.20	A	1
9.	Healthcare Coverage	3.06	A	3
10.	Health Screening	2.49	PA	9
11.	Nutrition Education/Weight Management Programs	2.15	PA	13
12.	Employee Participation	2.48	PA	10
13.	Education and Awareness Campaigns	2.52	A	7
14.	Allocated Budget for Health Program	2.42	PA	11
	Overall Mean	2.60	Available	

Legend:

Weight	**Score Range**	**Interpretation (I)**
5	4.51-5.00	VMA = Very Much Available
4	3.51-4.50	MA = Much Available

3	2.51-3.50	A	= Available
2	1.51-2.50	PA	= Partially Available
1	1.00-1.50	NA	= Not Available

Table 3 displays the composite mean rating on perceived administrative support for the existing hospital health promotion program. Generally, the obtained means ranged from the 2.41 to 3.17. The data suggest that the respondents perceived that the hospital administration does not fully support the existing hospital health promotion program. Generally, with its overall mean score of 2.61, the respondents perceived that the health promotion program is supported to some extent. In summary, all the interview data support the findings of this study concerning the area investigated. These findings should be considered by the administration when adopting a program that would promote, improve, and maintain employee health. The findings are parallel to those of authorities on the development of a workplace wellness programs. According to Henderson (2008, 55-59), in any endeavor that aspires to maintain and sustain a particular project or program, full participation of every member, employee, and even the key player is a necessity. The key players are the most significant since they have the ability to decide on major operations.

Table 3. Composite Mean Rating on Perceived Administrative Support to Existing Hospital Health Promotion Program

Indicators	Mean	I	Rank
1. Accessibility	3.18	S	1
2. Practicality and Suitability	2.63	S	3
3. Comprehensive Scope and Coverage	2.51	S	4
4. Focus on Employee's Welfare	2.44	LS	7.5
5. Employee Involvement	2.55	S	5
6. Sensitivity to Employee's Needs	2.47	LS	6
7. Quality of Service	2.46	LS	7.5
8. Continued Monitoring	2.41	LS	9
9. Cost, Equity, and Affordability	2.86	S	2
Overall Mean	2.61	Supported	

Legend:

Weight	**Score Range**	**Interpretation (I)**	
5	4.51-5.00	FS	= Fully Supported
4	3.51-4.50	MS	= Much Supported
3	2.51-3.50	S	= Supported
2	1.51-2.50	LS	= Less Supported
1	1.00-1.50	NS	= Not Supported

Sweeney and Witmer (1991, 527-540) argued that the seven dimensions of wellness should be developed and honed in every person especially the nurse-worker since, according to Venzon (2003) nurses are at all times prone to sickness with their exposure to various diseases within the hospital premises. Table 4 shows a Composite Mean Summary of the Respondents' Appraisal of the Extent of Workplace Wellness Promotion according to the seven dimensions of wellness in the hospital units. Informal conversation with the nurses revealed an interesting idea. Although the wellness promotion at this hospital is not that evident, they are fully aware of the benefits of having a functional workplace wellness program. They said they would like the hospital to implement one in order that avoid excess absenteeism and low performance. They also wanted to project the traditional image that Filipino nurses, whatever odds and shortcomings the workplace exposed them to, possess tender loving care qualities in the conduct of their nursing jobs. The study findings have implications for the administration and may challenge the key decision makers to consider having a concrete, comprehensive wellness program that could cover all the seven dimensions of well being and health and assure that nurses from this hospital will become models of optimum wellness in the nursing-caring services in this country and in the international arena. Table 5 is the composite summary of significant relationships between the availability of the hospital's basic health promotion program and extent of wellness promotion. Then, table 6 is the existing health promotion program and extent of wellnessis the composite summary of significant relationships between administrative support. The proposed workplace wellness program for nurses is designed based on the weak areas, six (6) partially available areas in the existing basic health promotion program, four (4) less supported areas of administrative support to the existing program, and on all the areas of workplace wellness promotion that are described as rarely promoted and sometimes promoted.

Table 4. Composite Mean Summary of the Respondents' Appraisal of the Extent of Workplace Wellness Promotion in the Hospital Units

Indicators	Mean	I	Rank
Physical	2.5	AE	4
Environmental	2.16	LE	7
Social	2.53	AE	3
Spiritual	2.61	AE	2
Emotional	2.28	LE	6
Intellectual	2.60	AE	1
Occupational	2.36	LE	5
Overall Mean	2.43	Low Extent	

Legend:

Weight	**Score Range**	**Interpretation (I)**
5	4.51-5.00	VHE = Very High Extent
4	3.51-4.50	HE = High Extent
3	2.51-3.50	AE = Average Extent
2	1.51-2.50	LE = Low Extent
1	1.00-1.50	NE = No Extent

Table 5. Composite summary of significant relationships between the availability of existing hospital's basic health promotion program and extent of wellness promotion

Availability of Existing Hospital's Basic Health Promotion Program	Extent of Workplace Wellness Promotion						
	Physical	Environmental	Social	Spiritual	Emotional	Intellectual	Occupational
Physical Activity Facilities and Access to Physical Activity Outside of Work Hours	S	S	S	S	S	S	S
Nutrition Education/Weight Management Program	S	S	N.S.	S	S	S	S
Written Policies on Physical Activity and Fitness Program	S	S	S	S	S	S	S
Allocated Budget for Health Program	S	S	N.S.	S	S	S	S
Employee Participation	S	S	N.S.	S	S	S	S
Health Screening	S	S	N.S.	S	S	S	S

Legend:

S - Significant

NS - Significant

Table 6. Composite summary of significant relationships between administrative support to the existing hospital health promotion program and extent of wellness

Administrative Support to the Existing Hospital Health Promotion Program	Extent of Workplace Wellness Promotion						
	Physical	Environmenal	Social	Spiritual	Emotional	Intellectual	Occupational
Continued Monitoring	S	S	S	S	S	S	S
Focus on Employee's Welfare	S	S	S	S	S	S	S
Quality of Service	S	S	S	S	S	S	S
Sensitivity to Employee's Needs	S	S	S	S	S	S	S

Legend:
S - Significant
NS - Significant

5 CONCLUSIONS AND FURTHER RESEARCH

This study was undertaken to determine whether health and wellness among nurses is promoted at a 300 bed government controlled city hospital in the Philipines. Specifically, the study investigated the nurses' rating on the availability of the hospital's existing program, their perceptions of administrative support of the program, and their appraisal of the scope of workplace wellness promotion in the hospital units. Significant relationships among those three variables were established using 0.05 level of significance. The results served as basis for the proposed workplace wellness program for nurses. Using descriptive-correlational method of research and guided by the Program Logic Model, the author's questionnaire was used for data collection. The sample was 131 out of 194 staff nurses who were randomly selected from the seven units of the hospital. Ranking, weighted mean, and Pearson coefficient were used to present and interpret the data. The existing health promotion program was given a rating of availability in the areas of response to cardiac events and emergency; written policies on tobacco use; healthcare coverage; health committee representation; worksite wellness program policy and worksite wellness plan; written policies on nutrition; education and awareness campaigns; and breaks or rest periods. However the nurses rated health screening; employee participation; allocated budget for health program research; written policies on physical activity and fitness programs; nutrition education/weight management programs; and physical activity facilities and access to physical activity facilities outside of work hours as partially available. As a whole, the hospital has available basic health promotion. The administrative support to the existing program was perceived to be available in areas of accessibility; practicality and suitability; employee involvement; and comprehensive scope and coverage. However, quality of service; focus on employees' welfare and sensitivity to employee's need; continued monitoring and cost, equity, and affordability were perceived to be less supported. The scope of workplace wellness promotion in the hospital units for intellectual; spiritual; and social wellness was sometimes promoted, while physical; occupational; emotional; and environmental wellness were rarely promoted. As a whole, workplace wellness promotion in the hospital was a limited. The proposed workplace wellness program for nurses was prepared based on the findings regarding weak areas: six (6) partially available areas in the existing program, four (4) less supported areas of administrative support for the existing program, and on all the areas of workplace wellness promotion that are described as rarely promoted and sometimes promoted. The following recommendations are offered by the researcher:

Present the findings of the study and the proposed workplace wellness program to the involved institution.

Test the proposed program's validity and applicability.

The hospital administration should adopt the proposed program.

The Department of Health should consider implementing the program in other government-run and private hospitals in the country to guarantee the promotion and development of wellness among Filipino nurses.

Replication studies are encouraged.

More in-depth analyses should be done to include other variables that the present research did not cover.

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AN ANALYSIS OF SELF-CARE KNOWLEDGE OF HEPATITIS B PATIENTS

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ABSTRACT

Background: Hepatitis B is one of the most significant diseases affecting the Asian population. Many people have insufficient knowledge about hepatitis. Its treatment has many limitations. Self-care of the patients plays an important role in improving their health and preventing the spreading of HBV to others.

Purpose: The aims of this study were to determine the levels of self-care knowledge in patients with hepatitis B and to identify the background characteristics that affected their self-care knowledge.

Methodology: A descriptive comparative research was designed to survey self-care knowledge of hepatitis B patients. Two hundred and thirty patients with hepatitis B at two large hospitals in the South of Vietnam participated. Patients were interviewed through a questionnaire. Data were analyzed by Stata 10.0 program with descriptive statistics, chi-square and Fisher.

Results: Only 59.1 per cent of the interviewed patients had good self-care knowledge. The rest had moderate or minimal self-care knowledge. Among these, the proportion of patients who had good knowledge about diet, personal hygiene, and management and monitoring of hepatitis B was low. By contrast, there were high proportions of patients who had good knowledge about exercise and rest and prevention of the spreading of hepatitis B virus (HBV) to others. Self-care knowledge of hepatitis B patients was affected by educational level, occupation, and previous health education.

Conclusions: Education should be increased to improve the self-care knowledge of patients with hepatitis B. Emphasis should be placed on increasing knowledge about diet, personal hygiene, and management and monitoring of hepatitis B. Hepatitis B patients who are farmers, housewives and retired people with low education levels and without previous health education should be given priority.

Recommendation: Further studies are necessary to learn about the relationship between self-care knowledge and practices of hepatitis B patients.

KEYWORDS

hepatitis B, patient, self-care knowledge, Vietnam

1 INTRODUCTION

Among hepatic viruses, hepatitis B virus (HBV) is the hepatic virus that is a great threat to the health of people worldwide (Bui, 2002). Two billion people worldwide have been infected with HBV. Among them, 350-400 million are chronic HBV carriers. Hepatitis B causes about 1 million deaths of HBV related liver failure, cirrhosis, and hepatocellular carcinoma (HCC) annually. There are about 50 million of new infected people each year. This disease has caused epidemics in parts of Asia and Africa; including Vietnam (World Health Organization [WHO], 2002). In Vietnam, hepatitis B is a significant health problem. The proportion of infected people is 10% to 15%. The number of infected people is continually increasing and becoming a burden for the country (Nguyen, 2004).

2 LITERATURE REVIEW

Hepatitis B

Hepatitis B is called a "silent infection" (Nguyen, 2004). There were many studies, carried out in many countries to survey the knowledge of people regarding hepatitis B. Most of those studies recognized that the knowledge of people, even hepatitis B patients, regarding the main sources of HBV transmission, treatment, and prevention is low (Thompson *et al.*, 2006; Han, Griffith and Westphalen, 2007). Also, their knowledge related to self-care was low. According to the results of a national survey that were presented at Digestive Diseases Week conference in Washington in May 30, 2007, knowledge and practice of chronic hepatitis B (CHB) patients regarding monitoring and compliance was low. Survey results showed:

- Sixty-nine percent (208/301) of patients could not name any specific test conducted to monitor their chronic HBV infection.
- When asked about treatment goals, only 29% (87/301) of patients had set their own personal goals regarding treatment of their CHB either in addition to or in the absence of physician-directed treatment goals.
- Among patients who had set lifestyle change goals, only 50% of patients planned to eat well, cease drinking alcohol and exercise, respectively.
- Only 55% of patients who had set medication compliance goals planned to accomplish the goals. Their knowledge about taking medication was also low.
- Fifty-four percent of participants were unsure why the drugs they were taking had been chosen. Therefore, they admitted frequently missing doses or taking them at the wrong time.

The results of this survey highlight a significant deficiency in patient understanding of hepatitis B treatment goals, testing and behaviors (Han, Griffith and Westphalen, 2007). One of the reasons may be lack of knowledge related to course of hepatitis B as well as self-care. Most authors suggested that appropriate health education programs should be developed for hepatitis B patients to improve their knowledge.

In Vietnam, almost previous hepatitis B related studies have focused on basic science or clinical research associated with hepatitis B. Few studies have surveyed self-care knowledge of hepatitis B patients. No one actually knows what the level of self-care knowledge in hepatitis B patients is. According to observation, Vietnamese hepatitis B patients have inadequate self-care. Many people do not know how to care for themselves even though there are health education programs for them. Patients' self-care knowledge affects their self-care practice. And it affects to the quality of care and outcomes of treatment. Therefore, the study of self-care knowledge of hepatitis B patients in Vietnam is essential to the country's health. Such studies will provide a base for developing and implementing health education programs for hepatitis B patients.

Theoretical Framework

The researcher selected Orem's Self-Care Deficit Nursing Theory (SCDNT) (Orem, 2001) as the most suitable theoretical framework for this study. This theory describes why and how people care for themselves (as cited in Taylor, 2006). It emphasizes self-care while this study surveyed self-care knowledge of hepatitis B patients. Self-care is the practice of activities that maturing and mature persons initiate and perform, within time frames, on their own behalf in the interest of maintaining life, healthful functioning, continuing personal development and well-being through meeting known requisites for functional and developmental regulation (Orem, 2001). The SCDNT has a fully explicated theoretical framework. This study studied the concepts of self-care agency and self-care requisites.

Each hepatitis B patient plays the role of self-care agent. According to Orem's explanation,, patients must gather enough knowledge related to hepatitis B in order to care for themselves well. They can obtain this knowledge from books and newspapers, nurse or doctor, and health education programs. Self-care requisites are the needs of daily living of hepatitis B patients. They are appropriate diet, good personal hygiene, balance between exercise and rest and understanding about management and monitoring of their hepatitis B. In addition, Orem suggested that self-care is not only care for oneself, but care for people around them (Orem, 2001) Care for others of hepatitis B patients is prevention of the spread of HBV to their family, friends and surrounding people. If a patient's self-care agency does not meet universal self-care requisites demands,a self-care deficit will exist. Then, nursing is needed to assist individuals in the provision of self-care (as cited in Foster and Bennett, 2002). But first, nurses should diagnose deficits in self-care knowledge and factors that affect to hepatitis B patient's self-care knowledge. Then, they can provide more effective education for hepatitis B patients.

Purpose of the study

This study described the self-care knowledge of hepatitis B patients. The specific aim of the study was to determine the levels of self-care knowledge in patients with hepatitis B and to identify background characteristics that affect their self-care knowledge

3 RESEARCH METHODOLOGY

A descriptive comparative research was designed for this study.

Data were collected by a questionnaire. The questionnaire was based on a review of literature related to self-care of patients with hepatitis B and Orem's Self-Care Deficit Nursing Theory (SCDNT). The questionnaire was reviewed by two medical specialists at Tropical Diseases Hospital and one nursing expert at Choray Hospital. The questionnaire includes two parts: background information and self-care knowledge. The part about self-care knowledge includes knowledge about diet, personal hygiene, exercise and rest, management and monitoring of hepatitis B, and prevention of the spreading of HBV to others. There was a total of 30 questions. A pilot study was carried out to test this questionnaire.

This study was conducted at 2 large public hospitals in Vietnam over one month's time. Two hundred and thirty patients with hepatitis B composed the convenience sample. They were adults with 18 years of age with medical orders at the time of survey. They were diagnosed with hepatitis B by physicians. Subjects who met the eligibility criteria were explained the purpose of the study, the survey process and benefits. Upon agreeing to join study, they were interviewed within 15-20 minutes.

Data were analyzed by using the Stata 10.0 program. Descriptive statistics were applied to analyze background characteristic of study sample. Then, chi-square and Fisher were used to identify background characteristics that affected hepatitis B patient's self-care knowledge.

4 FINDINGS AND DISCUSSION

The findings were categorized into 3 types: background characteristics, the levels of self-care knowledge, and background characteristics that affect to self-care knowledge.

Background characteristics of study sample

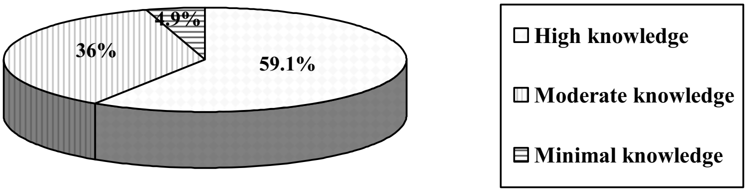
A total of 230 patients with hepatitis B completed the survey. There were 114 inpatients (49.6%) and 116 outpatients (50.4%). Of these, the majority of patients were male (59.1%), with a median age of 39.5 years. The youngest patient was 18 years old and the oldest patient was 82 years old. Over one-half of patients (55.2%) lived in urban areas (city, town). The general education level of patients was under high school (53%). Their occupation was fairly multiform. Among these, the majority of patients were farmers, housewives or retired people. Almost patients lived together with family or others (97%).

The majority of patients were diagnosed with hepatitis B over six months (83%). Seven-two point six percent of participants were chronic hepatitis B patients at the time of the survey. Among interviewed patients, there were 58.7% of patients who had received health education about hepatitis B. The major source of information was health staff (69.6%). One patient was educated through seminars of pharmaceutical companies.

The levels of self-care knowledge

Fifty-nine point one percent of interviewed patients had high levels of self-care knowledge. The rest of interviewed patients had moderate and minimal self-care knowledge. This result is illustrated in Figure 1.

Figure 1. The levels of self-care knowledge of hepatitis B patients



Hepatitis B patient's self-care knowledge included knowledge about diet, personal hygiene, exercise and rest, management and monitoring of hepatitis B, and prevention of the spreading of HBV to others. The proportion of patients who had high knowledge about exercise and rest, and prevention of the spreading of HBV to others was high. The results are detailed in Table 1.

Table 1. Hepatitis B patient's self-care knowledge

Knowledge	High level	Moderate level	Minimal level
Diet	51.3%	36.5%	12.2%
Personal hygiene	34.8%	33%	32.2%
Exercise and rest	83%	11%	6%
Management and monitoring of hepatitis B	34.4%	33%	32.6%
Prevention of the spreading of HBV to others	65.2%	22.6%	12.2%

Background characteristics affect to self-care knowledge

Hepatitis B patient's self-care knowledge was affected by education level, occupation, and previous health education (see Table 2). Patients' knowledge regarding diet and personal hygiene was different between inpatients and outpatients. The results are shown in Figures 2 and 3.

Table 2. Background characteristics affect to the levels of self-care knowledge.

Characteristic	Self-care knowledge – n (%)			p-value	Total (N=186)
	High	Moderate	Minimal		
Education level				**0.002**	
Under high school	44 (48.9)	40 (44.4)	6 (6.7)		90
High school	25 (55.6)	19 (42.2)	1 (2.2)		45
Above high school	41 (80.4)	8 (15.7)	2 (3.9)		51
Occupation				**0.000**	
Civil servant, worker	45 (83.3)	8 (14.8)	1 (1.9)		54
Farmer, housewife, retired people	30 (46.9)	28 (43.7)	6 (9.4)		64
Trader	20 (57.2)	13 (37.1)	2 (5.7)		35
Others (Students, freelancer)	15 (45.5)	18 (54.5)	0 (0.0)		33
Previous health education				**0.000**	
Yes	78 (68.4)	35 (30.7)	1 (0.9)		114
No	30 (48.4)	26 (41.9)	6 (9.7)		62
Don't know	2 (20)	6 (60)	2 (20)		10

Figure 2. Knowledge regarding diet between inpatients and outpatients

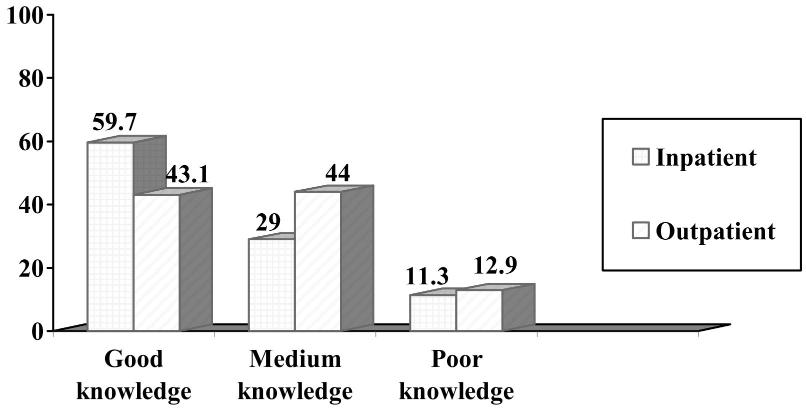
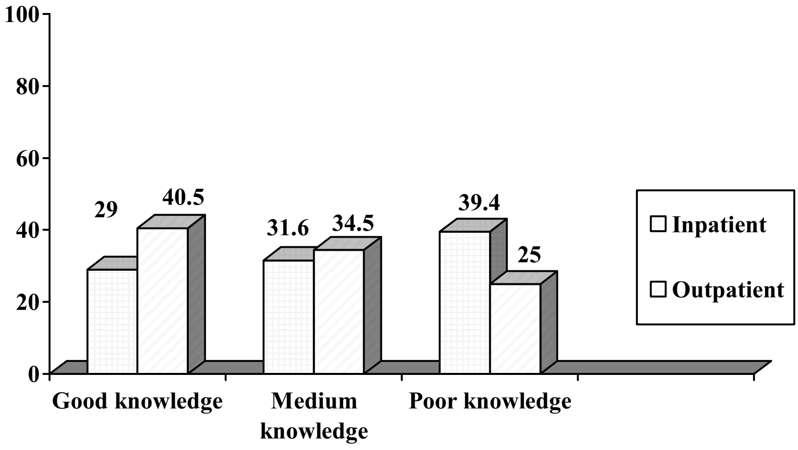


Figure 3. Knowledge regarding personal hygiene between inpatients and outpatients



Levels of self-care

This study showed that hepatitis B patients' self-care knowledge was not high. Nearly one-half of hepatitis B patients had moderate or minimal self-care knowledge. We believe that hepatitis B patients cannot understand how to take care of themselves well with moderate or minimal self-care knowledge.

Eighty-three percent of hepatitis B patients had high levels of knowledge about exercise and rest. This finding meets our expectation. In fact, almost people know the important of exercise and rest for the health. Means of communications such as television, radio or newspaper often comment about the effect of appropriate exercise and rest for the health. Vietnamese are interested in information related to the health, particularly disease sufferers as hepatitis B patients. Therefore, their knowledge about appropriate exercise and rest was high.

The proportion of patients who had high levels of knowledge about prevention of the spreading of HBV to others was fairly high (65.2%). According to them, the best way to prevent the spreading of their disease to others was to avoid sharing personal items, avoid contact with blood, to use condom if intercourse and to get vaccination. So, almost patients correctly identified the main sources of HBV transmission such as sexual activity, and blood. However, there was a large number of patients who didn't how to prevent the spreading of HBV. Vietnamese often live together with relatives. They, particularly people who live in rural or poverty often share personal items such as razor or nail clippers. Many patients thought that this sharing did not transmit HBV from them to their relatives. This opinion explains why the numbers of infected people still increase in Vietnam.

Knowledge about diet is paramount to hepatitis B patients because their diet directly affects outcomes of the treatment and care. Therefore, it is important to have correct diet for hepatitis B patients. However, there were only one-half of patients who had high levels of knowledge about diet. The majority of interviewed patients understood that patients with hepatitis B have to stop alcohol, smoking and strong coffee or strong tea. Conversely, nearly one-half of patients had limited knowledge about consumption of protein, fat, water and salt. Most patients were too careful about their disease. They followed a strict regimen. They omitted many foods. This is particularly common in the Vietnamese when they experience disease.

Besides knowledge about diet, knowledge about management and monitoring of hepatitis B is also important knowledge of hepatitis B patients. However, we found two-third of patients who had moderate or minimal levels of knowledge. This knowledge is really needed for patients with acute or chronic hepatitis B. If they have high knowledge, they can manage their hepatitis B to prevent complications (cirrhosis or liver cancer). Patients with acute and chronic hepatitis B account for nearly ninety percent in this study. Although almost hepatitis B patients had adequate awareness of the need to abide by physician's orders about using medicine and follow-up examination, many had poor awareness about monitoring their hepatitis B. They did not know what signs of hepatitis B they needed to notice. In fact, physicians and nurses rarely guide patients carefully to monitor signs and symptoms of hepatitis B. So, our results in knowledge about management and monitoring of hepatitis B reflected the reality in Vietnam. This result also shows that the voice of medical workers, especially doctors and nurses, is valued by hepatitis B patients. Thus, if doctors or nurses frequently provide self-care knowledge for hepatitis B patients, their knowledge will increase significantly.

Our study indicated that hepatitis B patients also lacked knowledge about personal hygiene. There were a large number of patients who stated that hepatitis B patients need to reduce or omit personal hygiene, particularly baths and shampoos. Moreover, almost patients didn't know how to care for their skin to decrease jaundice or itching. In fact, previous health education programs rarely addressed these points.

Background characteristics effect on self-care knowledge

In our study, we found that various background characteristics influenced self-care knowledge of hepatitis B patients. The first, there were significant differences in the levels of self-care knowledge between education levels. Patients with better education were more likely to have high self-care knowledge. This is not surprising as patients with better education are more likely to have read or heard about HBV infection in schools or in the mass media. Besides, patients with better education were more likely to understand the complexity of various aspects of HBV infection. This finding is consistent with the results of study that was carried out in Singapore (Wai *et al.*, 2005). According to this study, patients with better education were more likely to have a high knowledge score. Although that study did not survey self-care knowledge, it surveyed knowledge about transmission, and management of HBV infection. In our study, self-care knowledge included knowledge about management of hepatitis B and prevention of the spreading of HBV to others. The second, there were also significant differences between occupations. Patients who were civil servants or workers were more likely to have high self-care knowledge than patients who were farmers, housewives, or retired. And finally, patients who received previous health education had more self-care knowledge than those who had not. The difference was significant.

Our study also revealed that patients' knowledge regarding diet and personal hygiene was significantly influenced by the type of treatment - such as inpatient treatment or outpatient treatment. Inpatients were significantly more knowledgeable about diet than outpatients. By contrast, inpatients were less likely to have sufficient knowledge about personal hygiene than outpatients. In Vietnam, during hospitalization, hepatitis B inpatients eat meals that are provided by the nutrition department. We think that this factor influences knowledge about diet. So, inpatients understood diet more than outpatients. In the hospital, conditions are not conducive to personal hygiene. So, they did personal hygiene at the hospital less than at home. This practice could result in outpatients inpatients having less knowledge about personal hygiene less than outpatients.

According to Orem's self-care theory, every hepatitis B patient exhibits self-care agency. Hepatitis B patient's self-care agency is represented through self-care knowledge, attitude and behaviors. Self-care agency to engage in self-care is affected by basic conditioning factors such as gender, social-culture factors, health state, and resource adequacy (as cited in Taylor, 2006). So, the findings of this study about the effect of some background characteristics (education level, occupation, previous health education) on the levels of self-care knowledge are compatible with Orem's self-care theory. Our study found that hepatitis B patients lacked self-care knowledge. We recommend that nurses pursue teaching hepatitis B patients regarding self-care. Orem (2001) said that when self-care deficits exist, nursing is needed to assist individuals in the provision of self care (Orem, 2001). According to Orem, there are many methods that nurses can use to assist others (patients) such as doing for, guiding, supporting and teaching (Orem, 2001). Our findings showed deficits in self-care knowledge of hepatitis B patients. Teaching is the most effective helping method to improve self-care knowledge of hepatitis B patients. Therefore, nurses should provide more education for hepatitis B patients.

5 CONCLUSION AND FURTHER RESEARCH

This study's objectives were to determine the levels of self-care knowledge in patients with hepatitis B and recognize some influential background characteristics. One descriptive comparative survey research was designed to meet these objectives. There were 230 patients with hepatitis B in hepatitis departments of 2 large public hospitals in this study. They were interviewed by a questionnaire. Data was analyzed by SATA 10.0 program. Descriptive statistics and chi-square were applied. Finding were:

Fifty-nine point one percent of interviewed patients had high levels of self-care knowledge. Hepatitis B patients' self-care knowledge included knowledge about diet, personal hygiene, exercise and rest, management and monitoring hepatitis B and prevention of the spreading of HBV to others. Among these, the proportions of patients who had high knowledge about diet, personal hygiene, exercise and rest, management and monitoring hepatitis B and prevention of the spreading of HBV to others were 51.3%, 34.8%, 83%, 34.4%, 65.2%, respectively.

Hepatitis B patients' self-care knowledge was influenced significantly by education level, occupation and previous health education. Patients' knowledge regarding diet and personal hygiene was significantly influenced by type of the treatment.

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DEVELOPMENT OF SELF-CARE AGENCY THROUGH ENHANCEMENT OF MOTIVATION IN PEOPLE WITH SCHIZOPHRENIA

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ABSTRACT

Dorothea Orem, in her Self-care Deficit Nursing Theory (SCDNT), identified a "legitimate patient" as someone whose self-care agency, defined as a complex set of capabilities that enables individuals to perform self-care, is not adequate to meet his/her therapeutic self-care demands (Orem, 1991). Motivation is one of the foundational capabilities and power components of self-care agency. Human actions result from motivations and intentions that reflect personal values and desires (Taylor and Renpenning, 2011). Motivation, intention, and choice are essential for engagement in self-care actions. This theoretical paper examines (1) possible causes of motivational impairment in serious mental illnesses such as schizophrenia or schizoaffective disorder, (2) effects of impaired motivation in these disorders, (3) whether amotivation in schizophrenia is amenable to change, and (4) proposed supportive-developmental nursing technologies to enhance motivation. Self-Determination Theory (Ryan *et al.*, 2008) is explored as a comprehensive framework for supportive-developmental nursing technologies to help people with these disorders engage in health-promoting self-care actions. Specific supportive-developmental technologies proposed here include the Transtheoretical Model of Change (Prochaska and DiClemente, 1983) which identifies key stages of readiness for change (pre-contemplation, contemplation, preparation, action, and maintenance); and Motivational Interviewing (Miller and Rollnick, 2002) which is a way of "being

with" people to help them navigate the stages of change. Finally, (5) implications for practice and research are discussed.

It is well-documented that people with serious mental illness (SMI) have high rates of co-occurring medical conditions, inadequate or poorly coordinated health care (e.g., DeHert *et al.*, 2009), and typically live 25-30 years less than individuals in the general population (Colton and Manderscheid, 2006). According to Colton and Manderscheid, most premature deaths in this group result from physical conditions, especially cardiovascular disease, diabetes, and other treatable medical conditions.

Some of these health risks are thought to develop as a side effect of antipsychotic medications. However, people with SMI also may have poorer diets and more sedentary lifestyles (DeHert *et al.*, 2009). Developing ways to assist people address lifestyle factors that put them at increased risk for chronic disease and premature death is essential in working with this population.

A major obstacle in helping people with SMIs such as schizophrenia and schizoaffective disorder make healthy lifestyle changes is actually engaging them in the process of change. According to the D*iagnostic and Statistical Manual of Mental Disorders*, diagnostic criteria for these disorders include negative or deficit symptoms such as apathy, anhedonia, and/or amotivation (American Psychiatric Association, 2000). Amotivation has been identified as a significant symptom of schizophrenia that impacts nearly all aspects of behavior (Choi and Medalia, 2010). In one qualitative study, lack of motivation was a major factor that negatively influenced health-related decisions and behavior (Abed, 2010). For individuals whose psychotic symptoms are relatively well-managed by antipsychotic medication, addressing motivation to engage in healthy lifestyle choices may be key.

KEYWORDS

motivation, schizophrenia, self-care agency, supportive-developmental nursing system

1 CAUSES OF MOTIVATIONAL IMPAIRMENT IN SCHIZOPHRENIA

Barch (2008) noted a lack of research on motivation in schizophrenia spectrum disorders, in part because motivation is a complex construct that is difficult to quantify. The author suggested a need for further understanding of the neurobiological processes that may influence different components of emotion, reward, and motivation.

Medalia and Brekke (2010) reviewed theories that may help to explain impaired motivation in schizophrenia. Underlying physiological processes that may be implicated in motivational deficits in schizophrenia are complex. For example, people with schizophrenia may have inability to attend to important environmental stimuli, due to deficits in the "attentional network" of the brain (Liddle *et al.*, 2006). The attentional network is comprised of the cerebral cortex, temporoparietal junction and lateral frontal cortex, paralimbic cortex, amygdala and hippocampus, ventral striatum, thalamus and cerebellum. While Liddle *et al.* (2006) did not directly address motivation, the authors identified the ability to attend to stimuli as a predictor of motivation.

Another neurobiological process implicated in amotivation is the dopamine system, which is highly associated with the experience of pleasure and reward (Barch & Dowd, 2010; Gold, Waltz, Prentice, Morris, & Heerey, 2008). Some researchers suggested that people with schizophrenia may not be able to retain in working memory representations of the value of plans and outcomes (Gard, Fisher, Garrett, Genevsky, & Vinogradov, 2009; Gold *et al.*, 2008). Although individuals with schizophrenia do actually experience the feeling of pleasure or "affective valuation" in the moment, these individuals may have difficulty translating the valued experience into motivated, goal-driven behavior (Heerey and Gold, 2007; Gold *et al.*, 2008).

The role of antipsychotic medications, which decrease availability of dopamine in the brain, has been discussed in relationship to motivation. Typical antipsychotic medication, or first generation antipsychotics such as haloperidol, may contribute to amotivation since they have a greater likelihood of producing extrapyramidal side effects than do the atypical or second generation antipsychotics (Velligan and Alphs, 2008). Extrapyramidal side effects include blunted affect, akathisia, parkinson- like syndrome, and tardive dyskinesia. Liddle *et al.* (2006) concluded that atypical or second generation antipsychotic medications, although they do decrease dopamine, may actually alleviate motivational deficit. Velligan and Alphs (2008) suggested that the perceived benefits of second generation antipsychotics may result from less extrapyramidal side effects rather than actual treatment of negative symptoms. They further noted that individuals taking second generation antipsychotic medications were more likely to participate in psychosocial treatment and that the actual improvement in motivation may be a reflection of combination of second generation antipsychotics and psychosocial interventions.

Medalia and Brekke (2010) suggested that physiological processes interact with social contextual variables to affect motivation in individuals with schizophrenia. In the discussion of social context, these authors distinguished between extrinsic motivation (EM), the motivation to do something in expectation of a tangible reward such as money, and intrinsic motivation (IM), the motivation to do something because it is rewarding in itself. The authors emphasized the important role of EM, or social context, in the overall motivational response of individuals with schizophrenia. However, while EM is important, it is thought to be insufficient to sustain and generalize change over time (Medalia and Saperstein, 2011).

2 EFFECTS OF MOTIVATIONAL IMPAIRMENT IN SCHIZOPHRENIA

Regardless of what causes motivational impairment in schizophrenia, the effects of this impairment are well-documented. Motivational impairment has been identified as a reason for severe disability in schizophrenia (Velligan *et al.*, 2006). Specifically, motivation has consistently been identified as a mediator between cognition and functional outcome (Gard *et al.*, 2009; Yamada *et al.*, 2010).

In one longitudinal study, amotivation accounted for 74% and 72% of variance in functional outcomes at baseline and 6-month follow-up (Foussias *et al.*, 2011). The authors concluded that motivation plays an essential role in prediction of functional outcomes in schizophrenia. Other researchers identified motivation as having a similarly important role as social skills and social support in prediction of functional outcome (Gard *et al.*, 2009)

3 CAN MOTIVATION BE ENHANCED IN PEOPLE WITH SCHIZOPHRENIA?

A critical question about the role of motivational impairment in schizophrenia is whether or not motivation in this population is amenable to change. Recent studies have found that both external (EM) and internal motivation (IM) are malleable in schizophrenia (Choi and Medalia, 2010; Medalia and Saperstein, 2011).

According to educational psychology, conditions that promote IM and subsequent learning for people in general are those that provide personalization of tasks, increase value of tasks by linking them to everyday life, and support autonomy by providing choice (Medalia and Saperstein, 2011). In one study involving people with schizophrenia spectrum disorders, these same techniques used with a treatment group resulted in significantly greater self-report of IM (66% vs. 16%), perceived competency (90% vs. 18% improvement), and skill acquisition in contrast with the comparison group (Choi and Medalia, 2010; Medalia and Saperstein, 2011). These findings are extremely hopeful in that they suggest that motivation can be enhanced in this population.

Velligan *et al.,* (2006) stated that the fundamental disability in schizophrenia resides at the "intersection of cognitive and motivational processes" (481). These authors and others recommended targeting motivation as a way to maximize cognitive and functional outcomes for individuals with schizophrenia.

4 SUPPORTIVE-DEVELOPMENTAL NURSING TECHNOLOGIES TO ENHANCE MOTIVATION

Taylor and Renpenning (2011) stated that no one theory of motivation has been identified that best articulates with SCDNT. They suggested, however, that Self-Determination Theory (SDT) may be useful, since it emphasizes the importance of both internal and external motivation. Likewise, SDT has been proposed as one possible comprehensive framework for enhancing motivation in individuals with schizophrenia (Medalia and Brekke, 2010; Yamada *et al.*, 2010). Constructs central to this theory are autonomy, competence, and relatedness. SDT has been described as a general theory of motivation that has been applied in recent years to studies of health-related behavior change primarily in the general population (Ryan *et al.*, 2008). No studies have been found that incorporate use of SDT with Orem's SCDNT.

Ryan *et al.* (2008) asserted that, in order for health-related changes to be successfully initiated and maintained, individuals must arrive at personal valuation of the behaviors and affirmation of their importance. According to the authors, this requires autonomous, or internal, motivation. The authors identified "integrated regulation," in which individuals value a behavior as well as apply it consistently with other lifestyle values and patterns. In conjunction with autonomy, internalization of motivation requires that a person has a sense of competence, or confidence in the ability to change. Ryan *et al.* distinguished SDT from Bandura's (1989) self-efficacy theory. In Bandura's theory, self-efficacy, or belief in one's ability to change, is sufficient to implement change. In SDT, competency must be present in conjunction with autonomy to result in behavior change. Finally, SDT emphasizes the importance of the client-health-care provider relationship to facilitate change. This is consistent with other sources that identified the essential role of the therapeutic alliance in facilitating health-related behavior change for individuals with SMI (Hewitt and Coffey, 2005; McCabe and Priebe, 2004; McCabe *et al.*, 2012). Emphasis on the importance of the client-provider relationship is also consistent with SCDNT, which characterized the nurse-patient relationship as cooperative and collaborative (Orem, 1991).

SDT has been used as a framework for clinical research (e.g., Choi and Medalia, 2010; also see Ryan *et al.*, 2008). However, Vansteenkiste and Kennon (2006) suggested that SDT has been more concerned with theory than with practice. These authors proposed Motivational Interviewing (Miller and Rollnick, 2002) as a tangible way to apply SDT in the clinical setting.

Similarly, Markland, Ryan, Tobin, and Rollnick (2005) advocated SDT as a fitting theoretical framework for Motivational Interviewing, which has been criticized as being atheoretical.

Motivational Interviewing is a way of "being with" people that can help them navigate change (Miller and Rollnick, 2002). This model is often used in conjunction with the Transtheoretical Model of Change which describes stages of change as pre-contemplation, contemplation, preparation, action, and maintenance or relapse prevention (Prochaska abd DiClemente, 1983).

The Transtheoretical Model of Change was developed using factor and cluster analysis in multiple studies of smoking cessation (Zimmerman *et al.*, 2000). The Model has been validated, and used in studies addressing a full range of behaviors including smoking, substance use, contraceptive use, exercise and diet, among others (Prochaska *et al.*, 1994; Zimmerman *et al.*, 2000). This model also has been used with people with SMI, often in relationship to co-occurring SMI and substance disorders (Carey *et al.*, 2001; Nidecker *et al.*, 2008). The Transtheoretical Model of Change is based on the belief that change is not a discrete event but rather a process, and that an empathic, supportive approach in the context of a therapeutic relationship can help people move through the stages of change. This empathic, supportive approach is embodied in the tenets of Motivational Interviewing.

Principles of Motivational Interviewing include: expressing empathy, supporting self-efficacy, working with resistance, and developing discrepancy between current behavior and desired goals. This method, consistent with SDT, differs from a more traditional approach to motivating change. It does not externally impose change, which may be inconsistent with the person's values, but rather supports change based on the individual's goals and desires. Despite multiple methodological issues, research has provided at least moderate support for use of Motivational Interviewing with clients who have SMI experiencing a variety of health-related issues (e.g., Barrowclough *et al.*, 2001; Cleary *et al.*, 2008; Drymalski and Campbell, 2009; Methapatara and Srisurapanont, 2011; SAMHSA National Gains Center, 2011; Steinberg *et al.*, 2004).

SDT, the Transtheoretical Model of Change, and Motivational Interviewing are all based on the assumption that human beings are inherently oriented toward growth and change, and that an accepting and supportive environment is necessary to facilitate change (Ryan *et al.*, 2005). SDT and Motivational Interviewing were compared on all major constructs and determined to be philosophically congruent (Ryan *et al.*, 2005 Vansteenkiste and Sheldon, 2006).

5 IMPLICATIONS FOR PRACTICE AND RESEARCH

The integration of Self-Determination Theory with Prochaska and DiClemente's (1983) Transtheoretical Model of Change and Miller and Rollnick's (2002) Motivational Interviewing approach has potential to provide supportive-developmental nursing strategies in working with clients with schizophrenia, schizoaffective disorder, and other serious mental illnesses. No studies were found that integrate SCDNT with SDT, the Transtheoretical Model of Change, and/or Motivational Interviewing. However, exploration of the potential utility of these strategies to enhance motivation, viewed as a foundational capability and power component of self-care agency in people with SMI, is a worthwhile endeavor. The field of psychiatric-mental health nursing is a ready venue to apply these supportive-developmental strategies, and to evaluate their effectiveness and efficacy in the clinical setting.

Ryan *et al.* (2008) stated that behavioral change involves both initiating behavioral change, and maintaining these changes over time. On face value, these concepts are consistent with the estimative, transitional, and productive stages of deliberate action in SCDNT. Also, might there be a relationship between the stages of deliberate action described by Orem, and Prochaska and DiClemente's (1983) stages of readiness for change? Further exploration of motivation in the context of the stages of deliberate action would be productive.

Ryan *et al.* (2008) suggested research to further explicate the functional attributes of autonomy, competence, and supportive relationships, and the types of care that help to facilitate effective and long-lasting behavior change. Research has demonstrated that conditions that support autonomy and help to develop competence do in fact enhance motivation in persons with schizophrenia and lead to better functional outcomes such as skill acquisition (Choi and Medalia, 2010; Medalia and Saperstein, 2011). It would be instructive to explore specifically how autonomy and competence interact with motivation, as well as other foundational capabilities and power components of self-care agency; and what specific aspects and conditions of supportive-developmental nursing systems are required to help facilitate health-related behavior change in the population of people with schizophrenia/schizoaffective disorder.

Finally, Yamada *et al.* (2010) recommended exploring clinical and sociodemographic variables that may influence motivation. This suggests the need to explore the relationship between basic conditioning factors and motivation within a SCDNT framework.

6 CONCLUSIONS

Intention, motivation, and choice are critical aspects of self-care agency. This paper has explored ways in which motivation may be affected by a serious mental illness such as schizophrenia or schizoaffective disorder, possible causes and effects of impaired motivation in these disorders, whether amotivation in schizophrenia is amenable to change, and the potential utility of Self-Determination Theory (Ryan *et al.*, 2008) as a comprehensive framework for supportive-developmental nursing technologies to help people with these disorders engage in health-promoting self-care actions. Specific supportive-developmental technologies were proposed, including the Transtheoretical Model of Change (Prochaska & DiClemente, 1983, and Motivational Interviewing (Miller & Rollnick, 2002).

Nurses who use Self-Determination Theory as a guiding framework, and implement the specific principles and strategies encompassed in the Transtheoretical Model of Change and Motivational Interviewing, can potentially help people with schizophrenia/schizoaffective disorders identify intention to change, discover intrinsic motivation for change, and choose change strategies consistent with personal values and desires. Exploration of these strategies may expand the supportive-developmental technologies available to nurses, and may ultimately help people with serious mental illness engage in self-care practices that lead to improved health outcomes.

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THE PREVALENCE OF BEDRIDDENNESS AND LOCAL CONFINEMENT - A PILOT STUDY

PRÄVALENZERHEBUNG ZUR BETTLÄGERIGKEIT UND ORTSFIXIERUNG - EINE PILOTSTUDIE

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ABSTRACT

A basic need of human is activity, which loss has severe consequences for the art of shaping one's life. Nevertheless bedriddenness and thus increasing immobility which causes the need of long term care is paid little attention in nursing research. It is known that bedriddenness is a slow and hidden ongoing process, in which the person is increasingly confined to one location. In this process "*gradual local confinement*" was identified as the core category. The aim of the study was to determine the prevalence of bedriddenness and local confinement. The study is based on a quantitative cross-sectional survey, supplemented with expert interviews, carried out in 12 long-term care facilities in Vienna (n=3054). A standardized questionnaire was used to collect the data. Additional expert interviews with heads of long term care facilities were done to highlight influencing factors from the nursing perspective. The prevalence of bedriddenness in Vienna long-term care units is 49,8%, local confinement 61,8%. The results show that these phenomena manifest themselves independent of sex, body stature, length of stay and number of patients/nursing station. The study showed at the one hand the importance of these phenomena and is a basic fundament to develop preventive measures against them. On the other hand the developed instrument can be a basis for routine assessments in long term care units.

KEYWORDS

bedriddenness, dependency on care, local confinement, long-term care, immobility, prevalence investigation

ZUSAMMENFASSUNG

Bewegung stellt ein zentrales Grundbedürfnis des Menschen dar, deren Verlust schwerwiegende Folgen für das Leben und die Lebensgestaltung birgt. Dennoch wird Bettlägerigkeit und damit einhergehender Pflegebedürftigkeit noch immer kaum Beachtung geschenkt. Entscheidend für die Bettlägerigkeit ist der Eintritt in die Ortsfixierung, dh. der Mensch ist nicht mehr in der Lage sich selbst zu transferieren. Ziel dieser Pilotstudie, mittels quantitativer Querschnittserhebung in 12 Einrichtungen, war die erstmalige Erfassung der Prävalenz von Bettlägerigkeit und Ortsfixierung in der geriatrischen Langzeitpflege. Im Zuge dieser Studie wurden alle BewohnerInnen mittels eines standardisierten Fragebogens zu Bettlägerigkeit und Ortsfixierung eingeschätzt. Zusätzlich wurden ExpertInneninterviews mit Pflegedienstleitungen der teilgenommenen Einrichtungen geführt um erste Einflussfaktoren auf die Entstehung dieser Phänomene aus deren Sicht zu identifizieren. Mit dieser Untersuchung (n=3054) liegen erstmals Zahlen zur Prävalenz von Immobilität aus der österreichischen Altenpflege vor. Die Prävalenz von Bettlägerigkeit liegt bei 49,8%, die der Ortsfixierung bei 61,8%. Die Ergebnisse dieser Studie zeigen weiters, dass sich diese Phänomene unabhängig von Geschlecht, Alter, Körperstatur, Aufenthaltsdauer innerhalb der Einrichtung und PatientInnenzahl/Station manifestieren. Das im Zuge dieser Studie entwickelte Instrument kann als Grundlage für weitere Untersuchungen dienen, um Interventionen gegen Bettlägerigkeit und Ortsfixierung und daraus resultierende Pflegebedürftigkeit zu entwickeln, und um die Qualität der Pflege in Bezug auf die Vermeidung dieser Phänomene verbessern zu können.

SCHLÜSSELWÖRTER

Bettlägerigkeit, Immobilität, Ortsfixierung, Pflegebedürftigkeit, Prävalenzerhebung

1 EINLEITUNG

Bettlägerigkeit stellt ein zentrales Phänomen der Pflege dar und ist ein längerfristiger Daseinszustand, bei dem sich Betroffene die überwiegende Zeit des Tages und der Nacht im Bett aufhalten (Zegelin, 2010, 164).

Erste Untersuchungen zum Prozess des Bettlägerigwerdens (Zegelin, 2010) haben aufgezeigt, dass Bettlägerigkeit den Endpunkt eines meist schleichenden Prozesses zunehmender Immobilisierung darstellt (Zegelin, 2010, 13). Als zentrale Kategorie in diesem Prozess wird die allmähliche Ortsfixierung beschrieben. Ortsfixierte Menschen bestimmen nicht über ihren eigenen Bewegungsradius, sie bleiben auf der Stelle, ob in einem Rollstuhl oder auf einem Sessel sitzend und es fehlt ihnen an Unterstützung kurze Strecken selbstständig zu gehen (Abt-Zegelin und Reuter, 2009, 23).

Erste Studien und Praxisentwicklungsprojekte in Deutschland (Abt-Zegelin und Reuther, 2009; Reuther *et al.* 2010; Zegelin, 2012) beschäftigen sich mit ortsfixierten Menschen. Ganz im Gegensatz zu Österreich, wo weder das Phänomen der allmählichen Ortsfixierung noch der Bettlägerigkeit bis zum jetzigen Zeitpunkt untersucht wurde. Hier zeigen erste Ergebnisse, dass etwa die Hälfte der untersuchten BewohnerInnen in die Kategorie der Ortsfixierung fallen, sich der Prozess bis hin zur Ortsfixierung meist innerhalb eines Jahres entwickelt und dass die ersten Wochen nach Heimeinzug eine wichtige Weichenstellung bedeuten (Abt-Zegelin und Reuther, 19).

Es ist sehr schwierig konkrete epidemiologische Zahlen zu finden, wie viele Menschen in Österreich von Ortsfixierung und Bettlägerigkeit betroffen sind, da sie als besondere Gruppe bis zum jetzigen Zeitpunkt noch nicht erfasst wurden.

Aus diesem Grund sollte im Rahmen dieser Pilotstudie sollte eine erste Datenbasis im Hinblick auf die Verbreitung von Ortsfixierung und Bettlägerigkeit in Österreich geschaffen werden, die Ausgangspunkt weiterer Untersuchungen und Interventionsprogramme zu diesen Phänomenen sind.

2 FORSCHUNGSSTAND

Obwohl Bettlägerigkeit ein alltägliches Phänomen der Pflege darstellt, zeigte sich bei der Literaturrecherche in den Datenbanken Cinahl, PubMed und Medline, dass nur wenig Literatur zu Bettlägerigkeit aus rein pflegerischer Sicht existiert.

Es dominieren medizinorientierte Arbeiten zu den pathophysiologischen Auswirkungen des Liegens (Blazevich, 2006; Kortebein *et al.*, 2007; Brower, 2009) und Studien, die sich mit den psychosozialen Folgen von Immobilität (Cunningham, 2001; Kortebein et al, 2007; Fox *et al.*, 2009) oder diversen Trainingsprogrammen zur Steigerung der körperlichen Leistungsfähigkeit älterer Menschen beschäftigen (Tucker *et al.*, 2004).

So beginnt im Liegen schon nach 48 Stunden eine sogenannte Liegepathologie, die sich im weiteren Verlauf verfestigen kann und umfassende Konsequenzen für das Leben und die Möglichkeit der Lebensgestaltung mit sich bringt. Es kommt zu einer Veränderung des Atemzugvolumens, das Herzschlagvolumen geht zurück, die Thromboseneigung steigt, die Gefahr des Wundliegens wird groß und die Muskelmasse nimmt deutlich ab. Zudem droht Obstipation, die Wahrnehmung wird eingeschränkt und es treten kognitive und psychische Veränderungen auf (Rousseau, 1993, 174-175; Käppeli, 1999, 67; Kortebein *et al.*, 2008, 1078; Brower, 2009, 423; Zegelin, 2010, 30). Die ungünstigen Folgen einer Bettruhe betreffen somit alle Körpersysteme, das sensorische und psychische Empfinden von Menschen (Morton und Creditor, 1993, 220; Allen *et al.*, 1999, 1229-1232). Aus diesem Grund wird in der Medizin mittlerweile weitgehend auf die Verordnung einer Bettruhe verzichtet (Blech, 2007, 24). Dies wird gestützt durch Studien der australischen Fachzeitschrift "The Lancet", die den Nutzen von Bettruhe untersuchten und keinerlei Verbesserungen, jedoch starke Verschlechterungen durch das Liegen nachweisen konnten (Blech, 2007, 31).

Sehr viele medizinische Forschungsergebnisse zur Pathophysiologie des liegenden Körpers gehen auch auf Studien der Weltraumbehörde NASA zurück, die in den 40er Jahren groß angelegte Studien zur Immobilisierung in Zusammenhang mit Schwerelosigkeit durchgeführt hat (Rittweger *et al.*, 2005, 1019; Zegelin 2010, 29). Auch heute noch beschäftigt sich die Weltraumforschung intensiv mit der Testung von Folgen der Schwerelosigkeit auf den Menschen, deren Erkenntnisse wiederum auch für die Folgen der Bettlägerigkeit relevant sind.

In der Literatur fällt auch die enge Verbindung zwischen dem Grad der körperlichen Mobilität bzw. Pflegebedürftigkeit und den Phänomenen Einsamkeit und soziale Isolation bei alten Menschen auf (Fessmann, 2000; Hancock *et al.*, 2006; Baretta *et al.*, 2007;). Unter Pflegebedürftigkeit versteht man grundsätzlich den Zustand einer Person, "*die wegen (…) Krankheit oder Behinderung für die gewöhnlichen und regelmäßig wiederkehrenden Verrichtungen im Ablauf des täglichen Lebens auf Dauer (…) in erheblichem oder höherem Maße der Hilfe bedarf*" (Pschyrembel, 2007, 569). Zegelin (2010) bemerkt dazu, dass Bettlägerigkeit eng mit Pflegebedürftigkeit verbunden scheint, da ein bettlägeriger Mensch unfähig ist, einen normalen Tagesablauf zu gestalten und bei zahlreichen Aktivitäten (Körperpflege, Ausscheidung) Hilfe benötigt (Zegelin, 2010, 21).Viele pflegebedürftige Menschen fühlen sich oft hilflos und abhängig weil sie bei jeder Kleinigkeit auf Hilfe angewiesen sind, isolieren sich in Folge immer mehr von ihrem Umfeld, oder auch anderen Personen, um diesen nicht zur Last zu fallen. Da viele von ihnen die meiste Zeit des Tages ohne Ansprache in den Aufenthaltsräumen verbringen, fehlt ihnen oftmals auch die Perspektive. Dies kann mit ein Grund sein, warum manche das Bett nicht mehr verlassen, obwohl sie eigentlich physisch dazu in der Lage wären (Schnelle *et al.*, 2004, 235). Zegelin (2010) bemerkt dazu, dass fehlende Anregung und eine reizarme Umgebung zu einer Abstumpfung und Gewöhnung führen können (Zegelin, 2010, 34) und dass Menschen, die im Bett liegen, oftmals einen höheren Komfort empfinden können, als diejenigen, die fremdbestimmt und oftmals in unbequemen Stühlen sitzend den Tag verbringen "müssen" (Zegelin, 2010, 158). Gerade die Institutionalisierung scheint in diesem Zusammenhang einen wesentlichen Einflussfaktor darzustellen (Morton und Creditor, 1993, 220; Graf, 2006, 60; Zegelin, 2010, 18).

In der gegenwärtigen Literatur erfahren auch Bewegungsprogramme zur Steigerung der Leistungsfähigkeit und Mobilität älterer Menschen viel Aufmerksamkeit (Tucker *et al.*, 2004, 242-245; Brach *et al.*, 2009, 12-14; Mechling, 2009, 35;). Die beschriebenen Interventionen variieren jedoch sehr stark in ihren Vorgehensweisen.

Bei diversen Gruppentrainingsprogrammen, wie beispielsweise dem Programm "fit für 100", wird versucht durch gezielte Kräftigung der großen Muskelgruppen die Aktivitäten des täglichen Lebens so lange wie möglich eigenständig durchführen zu können. Dem Programm zu Folge verbessert sich unter anderem die Beinkraft und Standsicherheit und auch das subjektive Wohlbefinden der Personen (Mechling, 2009, 35). Auch Tucker *et al.* (2004) konnten mit dem Gruppenbewegungsprogramm "NGNA - Walking for Wellness" positive Ergebnisse erzielen und die Mobilität älterer Menschen verbessern (Tucker *et al.*, 2004, 242-244). Gute Erfolge erzielten auch Brach *et al.* (2009) in ihrer Studie, da nach Einführung eines präventiven, regelmäßigen Bewegungsprogrammes für ältere stationäre HeimbewohnerInnen Verbesserungen sichtbar wurden und auch persönliche Probleme besser bewältigt werden konnten (Brach *et al.*, 2009, 13-14). Die vorhandenen Programme zur Bewegungsförderung richten sich aber vorwiegend an "rüstige" ältere SeniorInnen in der Gruppe, orientieren sich alleine an den körperlichen Defiziten und lassen andere soziale bzw. psychologische Gründe, die eine Immobilität verstärken bzw. hervorrufen können, gänzlich außer Acht (Reuther, 2008, 11). Für die Gruppe der bettlägerigen bzw. ortsfixierten Menschen mit fortschreitender Immobilität existieren noch unzureichende Angebote.

Wie der Forschungsstand zu Bettlägerigkeit aufzeigt, handelt es sich bei diesem Phänomen nicht um einen Begriff der rein als Stichwort oder Kategorie in der bisherigen Literatur zu finden ist. Eine Beschäftigung mit dem Phänomen Bettlägerigkeit geht weit über eine klassische Literaturrecherche hinaus, und beinhaltet zudem auch noch andere Recherchefelder und vorhandene Nomenklaturen (wie Pflegekonzepte bzw. Konzeptanalysen) im Pflegebereich. Die hier aufgezeigten Erkenntnisse können als Grundlage verstanden werden das Phänomen besser verstehen zu können und zeigen auf, dass eine Auseinandersetzung mit Bettlägerigkeit bis zum jetzigen Zeitpunkt noch zu wenig erfolgte. Zudem verwundert es, dass Bettlägerigkeit bisher in der internationalen Pflegewissenschaft nicht hinterfragt wurde, obwohl in der Perspektive der Pflege die Anliegen der Alltagsbewältigung im Blickpunkt des Interesses liegen (Zegelin, 2010, 53).

Zegelins Aufzeigen der Betroffenenperspektive bettlägeriger Menschen (2010) lieferte erstmals einen tieferen Einblick in das Phänomen und dient als theoretische Grundlage für die Auseinandersetzung innerhalb dieses Forschungsprojekts.

3 THEORETISCHER HINTERGRUND

Das von Zegelin (2010) entwickelte Phasenmodell, in dem erstmalig der Prozess des Bettlägerigwerdens beleuchtet wird, bildet den theoretischen Hintergrund dieser Studie (Zegelin, 2010).

Strikte Bettlägerigkeit ist ein Endzustand und eine zunehmende Immobilisierung entwickelt sich schleichend und prozesshaft über fünf bestimmte Phasen: Instabilität, Ereignisphase, Immobilität im Raum, Ortsfixierung und schlussendlich Bettlägerigkeit (Zegelin, 2010, 114). Für die vorliegende Studie sind vor allem die Phasen 4 "Ortsfixierung" und 5 "Bettlägerigkeit" relevant.

Den Hauptbestandteil der Untersuchung des Prozesses der Bettlägerigkeit bildeten 32 Interviews mit bettlägerigen, älteren Menschen (19 Männer, 13 Frauen), im Alter von 62 bis 98 Jahren, die teilweise daheim oder in Institutionen lebten.

Die Entwicklung hin zur "*dauerhaften Lägerigkeit*" ist "*durch den Umstand der Ortsfixierung gekennzeichnet*". Im Vordergrund steht dabei die Angewiesenheit auf einen Ort (Zegelin, 2010, 166).

Dass Menschen bettlägerig werden passiert meist schleichend, sie sind zusehends an einen Ort verwiesen, von dem sie sich nicht mehr fortbewegen können und dieser Ort reduziert sich später zusehends auf einen Raum, ein Sitzmöbel und schließlich gänzlich das Bett (Zegelin, 2010, 17).

In der ersten Phase der Instabilität manifestiert sich die zunehmende Beschränkung auf einen Ort, zusätzlich machen sich bei den Betroffenen Angst, Vorsicht und Organisation von Hilfe bemerkbar (Zegelin, 2010, 114-115). Oftmals führt in Folge ein bestimmtes Ereignis (z.B. Krankenhausaufenthalt) zu einer weiteren Verschlechterung der Gehfähigkeit, welches in diesem Zusammenhang die zweite Phase darstellt (Zegelin, 2010, 115-119). Eine weitere Bewegungseinschränkung erfahren betroffene Menschen in der dritten Phase, der Immobilität im Raum. Hier fällt es Betroffenen zusehends schwer zwischen Rollstuhl und Sessel oder Bett zu wechseln. Anfänglich gelingt dies noch unter Zuhilfenahme kleinerer Hilfen wie Abstützmöglichkeiten oder Transferhilfen (Zegelin, 2010, 119-120).

Entscheidend ist dann der Eintritt in die Ortsfixierung, die vierte Phase im Prozess des Bettlägerigwerdens. In dieser Phase sind die Menschen nicht mehr in der Lage sich selbst zu transferieren. Sie können selbstständig nicht mehr zwischen Orten wie Rollstuhl, Bett, Sitzmöbeln oder Toilette wechseln. Betroffene können nicht mehr gehen, oft auch nicht mehr stehen, bleiben "*am Ort sitzen*" und benötigen für den Wechsel Hilfe. Viele Menschen verbringen dann den überwiegenden Teil des Tages im Rollstuhl sitzend oder halten sich in wenigen Fällen auch tagsüber im Bett auf. Trotzdem gelten diese Menschen als "mobilisiert", obwohl sie nur passiv "herausgesetzt" werden und nicht mehr über ihren eigenen Bewegungsradius bestimmen können. Oftmals fragen Betroffene nicht mehr nach Hilfe bei einem Ortswechsel, weil sie entweder keine Arbeit machen wollen oder sich mit dieser Situation gezwungenermaßen zurechtgefunden haben. Gerade in institutionellen Pflegeeinrichtungen ist der Tagesablauf oftmals funktional ausgerichtet, sodass die BewohnerInnen zu vorgegebenen Zeiten aus dem Bett in den Rollstuhl und wieder retour transferiert werden. Die Ortsfixierung geschieht meist schleichend und bildet den entscheidenden Eintritt in die strikte Bettlägerigkeit. Gerade in dieser Phase können zahlreiche Faktoren (Rücksichtnahme der Betroffenen, Einstellung und Kompetenz der Pflegenden...) eine strikte Bettlägerigkeit beschleunigen aber auch aufhalten. Oftmals korrespondiert das Verhalten der alten Menschen mit den Erwartungen des Umfeldes. Wenn nichts Sinnvolles mehr passiert, kann auch liegen geblieben werden (Zegelin, 2010, 128-140).

Erst in der letzten Phase kommt es zum Dauerliegen. Die Betroffenen verbringen 24 Stunden am Tag und in der Nacht im Bett. Die meisten Personen haben ihre Ansprüche auf ein Minimum heruntergeschraubt und sehen ihr Schicksal als unausweichlich. Sie verlassen nicht einmal zur Ausscheidung das Bett, da sie mit Inkontinenzhilfen versorgt werden. Außerdem haben diese Menschen Probleme bei der Zurückverfolgung der Zeit, deren Ursachen in der Monotonie des Alltags und den geringen Reizanflutungen und Abwechslungen zu finden sind (Zegelin, 2010, 140-145).

Zegelin zeigt mit ihrer Studie auf, dass Bettlägerigwerden ein Verlaufsgeschehen darstellt und dass vielfach "*seelische und körperliche Befindlichkeiten, strukturelle und soziale Aspekte*" mit Umfeldbedingungen interagieren (2010, 159). Mit dem Konzept der allmählichen Ortsfixierung rückt Zegelin erstmals die große Anzahl älterer ortsfixierter Menschen in den Mittelpunkt, die zwar aus dem Bett "herausgesetzt" werden, aber nicht über ihren eigenen Bewegungsradius bestimmen können und macht auf die Tatsache aufmerksam, dass viele dieser Personen in Pflegeheimen verhältnismäßig viel Zeit im Bett verbringen, ohne dass die Gründe dafür geklärt sind (Zegelin, 2010, 128).

Abschließend ist hinzuzufügen, dass sowohl Bettlägerigkeit als auch Ortsfixierung in drei Schweregrade unterteilt werden können, deren Definitionen die Grundlage für die Erfassung ortsfixierter und bettlägeriger Menschen in österreichischen Langzeitpflegeeinrichtungen darstellen und im Methodenteil dieses Artikels näher erläutert werden.

4 FORSCHUNGSZIEL UND FORSCHUNGSFRAGEN

Ziel dieser Studie ist es eine erste Datenbasis in Hinblick auf die Verbreitung der Phänomene Bettlägerigkeit und Ortsfixierung in Österreich zu schaffen, da weder die Prävalenz des Phänomens der Bettlägerigkeit, noch das der Ortsfixierung an sich bekannt ist.

Weiters soll mit dieser Prävalenzerhebung geprüft werden, inwiefern naheliegende Einflussgrößen, die in der Studie von Zegelin (2010) diskutiert werden, relevant für das Auftreten von Bettlägerigkeit und/ oder Ortsfixierung sind.

Demnach waren folgende Forschungsfragen für die Untersuchung leitend:

1. Wie viele BewohnerInnen (absolut und relativ) der *Teilunternehmung Geriatriezentren und Pflegewohnhäuser der Stadt Wien mit sozialmedizinischer Betreuung* sind bettlägerig bzw. ortsfixiert?
2. Haben die untersuchten Variablen *Geschlecht, Körperstatur, Aufenthaltsdauer innerhalb der Einrichtung und PatientInnenzahl/-Station* Einfluss auf Bettlägerigkeit und Ortsfixierung?

5 METHODIK

Vorliegender Studie liegt im Rahmen der quantitativen Forschung ein multizentrisch deskriptives Studiendesign zu Grunde. Die Erhebung wurde als Querschnittsstudie in 12 Institutionen mittels eines standardisierten Fragebogens durchgeführt, in dem alle BewohnerInnen hinsichtlich Ortsfixierung und Bettlägerigkeit (laut Definitionen) eingeschätzt wurden.

Bei dieser Studie handelt es sich um eine Vollerhebung in allen Geriatriezentren und Pflegewohnhäusern der "*Teilunternehmung Geriatriezentren und Pflegewohnhäuser der Stadt Wien mit sozialmedizinischer Betreuung*" im Sinne einer Punktprävalenzerhebung. Unter Punktprävalenz versteht man die Häufigkeit des Vorkommens eines gesundheitsbezogenen oder anderen Ereignisses in einer gegebenen Population zu einem bestimmten Zeitpunkt (Eberl, 2009, 108). Die Prävalenz erfasst die zum Zeitpunkt der Datenerhebung zu messende Häufigkeit einer Erkrankung in einer definierten Bezugsgruppe (Panfil, Mayer, 2007, 83).

Prävalenzstudien wie die vorliegende sind nicht nur für die Pflege, sondern auch für die Gesellschaft und daraus resultierend für die Gesundheitspolitik relevant, da sie die Häufigkeit des Vorkommens von Ortsfixierung und Bettlägerigkeit aufzeigen, die jeweils Formen der Pflegebedürftigkeit darstellen und teilweise erhebliche Kosten verursachen (Eberl, 2009, 115).

Erhebungsinstrument und Vorgehensweis

Zur Datenerhebung wurde ein Instrument zur Einschätzung des Status der BewohnerInnen bezüglich Bettlägerigkeit und Ortsfixierung entwickelt. Die

Definitionen der beiden Phänomene, die dem Instrument zugrunde liegen, basieren auf dem theoretischen Modell von Zegelin (2010).

Bettlägerigkeit

Zegelin (2010) definiert Bettlägerigkeit als "*längerfristigen Daseinszustand, bei dem sich Betroffene die überwiegende Zeit des Tages und der Nacht im Bett aufhalten*" (164). Man kann dabei zwischen einer leichten, mittelschweren und schweren Form unterscheiden:

Leichte Form der Bettlägerigkeit: "*In einer leichten Form der Bettlägerigkeit kann der Mensch ungefähr 4 bis 5 Stunden außerhalb des Bettes sein, etwa in einem Rollstuhl oder in einem Sessel sitzend*".

Mittelschwere Form der Bettlägerigkeit: "*Bei einer mittleren Ausprägung verlässt der Mensch für wenige Handlungen kurze Zeit das Bett, etwa um auszuscheiden, zur Körperpflege oder zum Essen*".

Schwere Form der Bettlägerigkeit: "*In einer strikten (schweren) Form von Bettlägerigkeit steht der Mensch überhaupt nicht mehr auf*" - verbringt also 24/h Tag im Bett (Zegelin, 2010, 164-165).

Ortsfixierung

Als ortsfixiert gelten Menschen, die sich nicht mehr alleine von einem Ort (Sessel, Bett …) fortbewegen können, also unfähig sind den Transfer selbstständig durchzuführen. Ortsfixierung endet letztlich mit einem strikten Liegen im Bett (Zegelin, 2010, 128). Auch hier können drei Schweregrade unterschieden werden:

Leichte Form der Ortsfixierung: Hier bewegt sich der Bewohner in weiten Teilen selbstständig und bestimmt über seinen Bewegungsradius selbst. Er benötigt aber Hilfe beim Transfer.

Mittelschwere Form der Ortsfixierung: Hier fährt der Bewohner in einem geringen Maße (kurze Strecken) den Rollstuhl noch selbständig. Sein Bewegungsradius innerhalb der Einrichtung ist aber eingeschränkt.

Schwere Form der Ortsfixierung: Hier verbringt der Bewohner die überwiegende Zeit des Tages an einem Ort (im Stuhl/-Rollstuhl) ohne sich fortzubewegen. Er bewegt den Rollstuhl nicht selbst (Zegelin, 2010, 128).

Basierend auf diesen Definitionen wird mit dem Instrument folgendes erhoben:

- Status der Bettlägerigkeit jetzt und vor 6 Monaten
- Status der Ortsfixierung jetzt und vor 6 Monaten
- Vorübergehende Bettruhe (durch akute Erkrankung oder vorausgegangene Operation)

Zusätzlich wurden vier mögliche Einflussgrößen auf die Entstehung von Ortsfixierung und Bettlägerigkeit erhoben:

- Geschlecht
- Körperstatur [5)]
- Aufenthaltsdauer innerhalb der Einrichtung
- PatientInnenzahl der Station

Die Datenerhebung erfolgte zu einem bestimmten Zeitpunkt mittels eines standardisierten Fragebogens, parallel und zeitnah innerhalb von 14 Tagen in allen teilnehmenden Einrichtungen. Dazu wurden vorab 14 RaterInnen, Angestellte der teilgenommenen Einrichtungen, die sich freiwillig zur Verfügung stellten an der Erhebung mitzuwirken, geschult. Im Rahmen von Teambesprechungen, bei denen mindestens zwei Pflegepersonen anwesend sein mussten, wurde dieser standardisierte Fragebogen für jede/n Bewohner/in, in Übereinstimmung der in den Teamsitzungen beteiligten Pflegekräfte, von den RaterInnen ausgefüllt. Eine Dokumentenanalyse war nicht vorgesehen.

Sample

In diese Vollerhebung wurden alle BewohnerInnen der Geriatriezentren und Pflegewohnhäuser der Stadt Wien mit sozialmedizinischer Betreuung eingeschlossen, die am Erhebungstag ganztägig in der Einrichtung lebten. Ausgeschlossen wurden diejenigen BewohnerInnen, die den Erhebungstag nicht ganztägig in der Einrichtung verbrachten und BewohnerInnen der Kurzzeitpflege, Urlaubsbetreuung sowie Wachkoma-, und LangzeitbeatmungspatientInnen. Diese Geriatriezentren und Pflegewohnhäuser, mit jeweils maximal 350 Betten pro Einrichtung, richten sich an pflegebedürftige Menschen, bei denen eine Betreuung zu Hause nicht mehr möglich ist. Da die bestehenden Einrichtungen teilweise nicht mehr den Erfordernissen der gegenwärtigen Zeit entsprechen, werden derzeit zahlreiche Geriatriezentren saniert sowie Neubauten, sogenannte Pflegewohnhäuser errichtet.

Datenauswertung

Die Datenauswertung erfolgte mittels Methoden der deskriptiven Statistik. Für die statistische Auswertung wurde das Programm "Statistical Package for the Social Sciences (SPSS 15.0) verwendet. Dazu wurden Häufigkeitsauszählungen durchgeführt. Für die Errechnung möglicher Zusammenhänge ordinaler und metrischer Daten wurden Korrelationsanalysen angewendet.

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5) *Die Körperstatur setzt sich aus dem Gewicht und der Größe zusammen und richtete sich nach der jeweiligen Einschätzung der Pflegepersonen.*

6 ERGEBNISSE

Merkmale der BewohnerInnen

Im Rahmen der Prävalenzerhebung konnte der Mobilitätszustand von 3054 Personen erhoben werden. Das Sample besteht zu einem Viertel (26,9%) aus Männern und zu drei Viertel (72,9%) aus Frauen. 27,8% der BewohnerInnen hatten eine leichte, 44,0% eine mittlere und 28,1% eine schwere Körperstatur. 13,2% der BewohnerInnen lebten zum Zeitpunkt der Erhebung weniger als 6 Monate in der Einrichtung. 10,6% zwischen 6 und 12 Monaten, 14,4% 1 bis 2 Jahre, 23,0% 2 bis 4 Jahre und 38,8% der BewohnerInnen lebten schon länger als 4 Jahre innerhalb der Institution. Die PatientInnenzahl/Station variierte zwischen 12 und 43 Personen, wobei 13,3% auf Stationen mit bis zu 20 Personen/Station lebten, 59,6% auf Stationsgrößen zwischen 21 und 30 Personen/Station und 27,2% auf Stationen mit mehr als 30 Personen/Station. Die Frage ob die BewohnerInnen eine vorübergehende Bettruhe einhalten müssen ist eindeutig mit nein (98,3%) zu beantworten. Nur 1,6% müssen eine vorübergehende Bettruhe aufgrund einer Erkrankung und 0,1% aufgrund einer vorausgegangenen Operation einhalten.

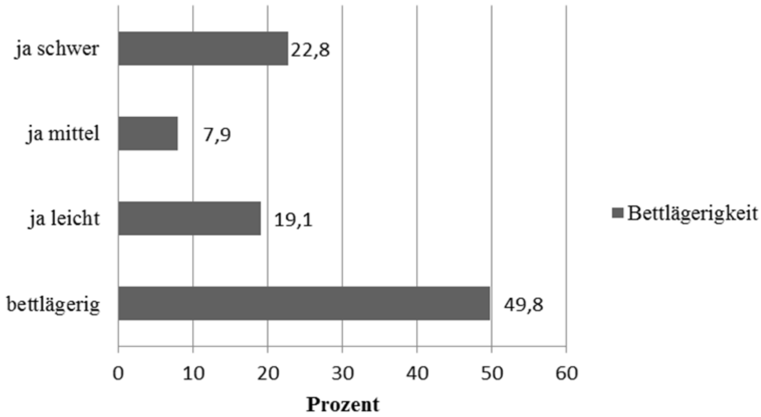
Abbildung 1. Merkmale der BewohnerInnen

Merkmale der BewohnerInnen			Anzahl (n)
Geschlecht	weiblich	72,9%	n= 3054
	männlich	26,9%	
Körperstatur	leicht	27,8%	n= 3032
	mittel	44,0%	
	schwer	28,1%	
Aufenthaltsdauer	weniger als 6 Monate	13,2%	
	6 bis 12 Monate	10,6%	n= 3048
	1 bis 2 Jahre	14,4%	
	2 bis 4 Jahre	23,0%	
	länger als 4 Jahre	38,8%	
PatientInnenzahl/Station	bis 20 Personen/Station	13,3%	n= 3054
	21-30 Personen/Station	59,6%	
	über 30 Personen/ Station	27,2%	
Bettruhe	nein	98,3%	n=3042
	wegen einer Erkrankung	1,6%	
	wegen vorausgegangener OP	0,1%	

Bettlägerigkeit

Zum Zeitpunkt der Erhebung waren 49,8% der BewohnerInnen bettlägerig. Von diesen Personen waren 19,1% leicht bettlägerig, 7,9% mittelschwer und 22,8% schwer bettlägerig (siehe Abbildung 2).

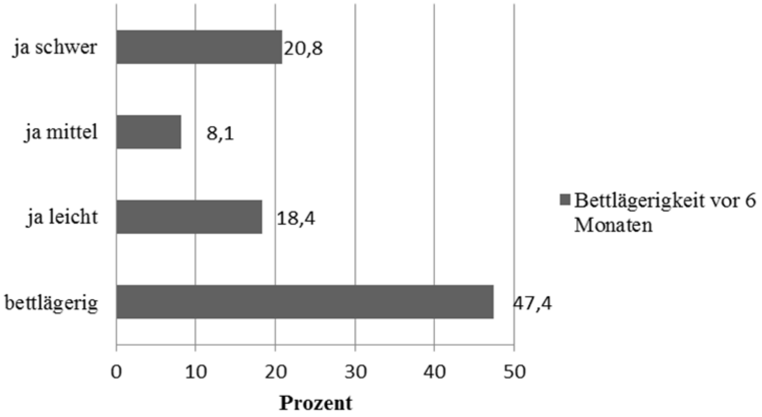
Abbildung 2. Bettlägerigkeit (n=2609)



6 Monate zuvor waren 47,4% der BewohnerInnen bettlägerig, 18,4% leicht, 8,1% mittelschwer und 20,8% schwer bettlägerig (siehe Abbildung 3). Die Bettlägerigkeit hat sich innerhalb von 6 Monaten nur geringfügig um 2,4 Prozentpunkte erhöht. Die mittelschwere bis schwere Bettlägerigkeit hat sich um 1,8 Prozentpunkte gesteigert.

Während bei 55 Personen innerhalb von 6 Monaten eine Zustandsverbesserung eingetreten ist, kann bei 152 Personen eine Zustandsverschlechterung nachgewiesen werden. Von diesen 152 Personen haben sich 90 Personen um eine Einstufung (zB: leichte Form zu mittelschwerer Form), 39 Personen um zwei Einstufungen und 23 Personen um drei Einstufungen verschlechtert.

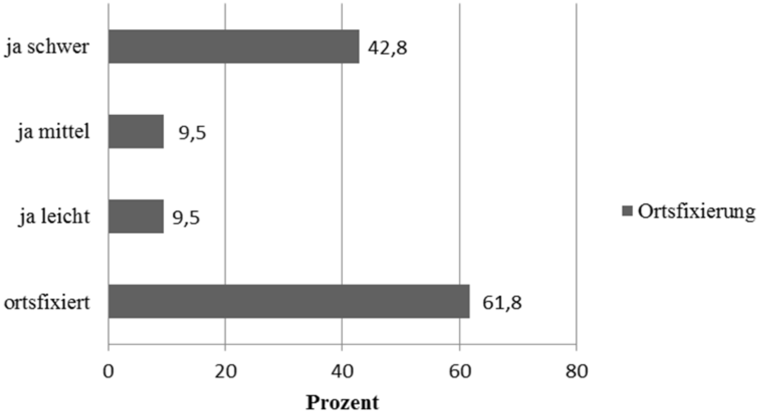
Abbildung 3. Bettlägerigkeit vor 6 Monaten (n=2609)



Ortsfixierung

Zum Zeitpunkt der Erhebung waren 61,8% der BewohnerInnen ortsfixiert. Von diesen Personen waren 9,5% leicht, 9,5% mittelschwer und 42,8% schwer ortsfixiert (siehe Abbildung 4).

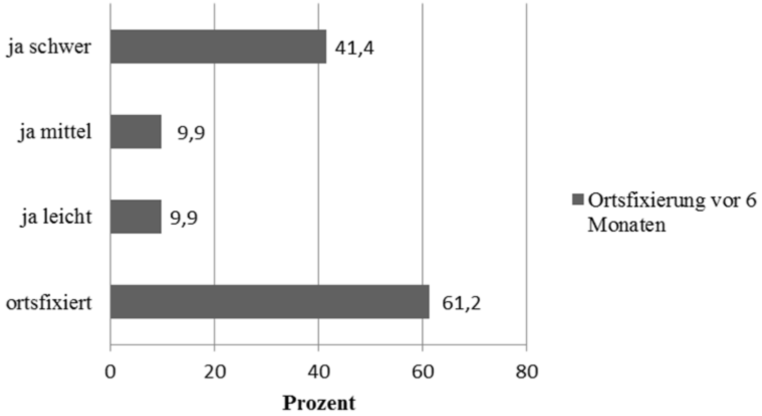
Abbildung 4. Ortsfixierung (n=2600)



6 Monate zuvor waren 61,2% der BewohnerInnen ortsfixiert, 9,9% leicht, 9,9% mittelschwer und 41,4% schwer ortsfixiert (siehe Abbildung 5). Hier zeigt sich, dass sich auch die Ortsfixierung innerhalb von 6 Monaten nur geringfügig um 0,6 Prozentpunkte verschlechtert hat. Bei der mittelschweren bis schweren Ortsfixierung zeigt sich eine Steigerung um einen Prozentpunkt.

Bei 113 Personen ist eine Zustandsverschlechterung innerhalb der letzten 6 Monate eingetreten, wobei sich 52 Personen um eine Einstufung (zB: mittelschwere Form zu schwerer Form), 27 BewohnerInnen um zwei Einstufungen und 34 BewohnerInnen um drei Einstufungen verschlechtert haben.

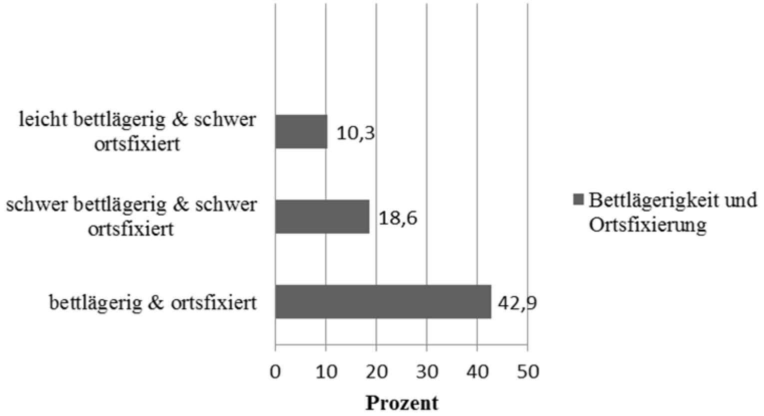
Abbildung 5. Ortsfixierung vor 6 Monaten (n=2595)



Bettlägerigkeit und Ortsfixierung

Zum Zeitpunkt der Erhebung waren 42,9% der BewohnerInnen sowohl bettlägerig als auch ortsfixiert. Von diesen Personen waren 18,6% sowohl schwer bettlägerig als auch schwer ortsfixiert. Von einer schweren Ortsfixierung und einer leichten Bettlägerigkeit waren 10,3% der BewohnerInnen betroffen. Anhand der nachstehenden Abbildung 6 zeigt sich, dass vor allem eine schwere Form der Bettlägerigkeit in Kombination mit einer schweren Ortsfixierung auftritt.

Abbildung 6. Bettlägerigkeit und Ortsfixierung (n=3032)



Erwartbar war der deutliche Zusammenhang zwischen Bettlägerigkeit und Ortsfixierung. Die Korrelationstest zeigen, dass je schwerer eine Person zum Zeitpunkt der Erhebung bettlägerig war, desto schwerer war er/sie auch zu diesem Zeitpunkt ortsfixiert (rho= 0,563). Je schwerer jemand vor 6 Monaten bettlägerig war, desto schwerer war er/sie auch zum Zeitpunkt der Erhebung bettlägerig (rho= 0,902). Je schwerer eine Person vor 6 Monaten ortsfixiert war, desto stärker war er/sie auch zum Erhebungszeitpunkt ortsfixiert (rho= 0,914). Und je schwerer jemand vor 6 Monaten ortsfixiert war, desto schwerer war er/sie auch vor 6 Monaten bettlägerig (rho= 0,591).

Zusammenhang zw. Bettlägerigkeit/-Ortsfixierung und den untersuchten Einflussfaktoren

Durch die zusätzlich erhobenen Variablen Geschlecht, Körperstatur, Aufenthaltsdauer und PatientInnenzahl/Station sollten mögliche Zusammenhänge zwischen diesen Größen und der Entstehung von Ortsfixierung und Bettlägerigkeit nachgewiesen werden. Im Rahmen dieser Untersuchung konnte jedoch festgestellt werden, dass nur vernachlässigbare bis keine Zusammenhänge zwischen Bettlägerigkeit bzw. Ortsfixierung und den erhobenen naheliegenden Einflussgrößen bestehen.

So sind zwar Frauen sowohl eher schwer bettlägerig als auch schwer ortsfixiert, man kann hierbei aber in beiden Fällen nur von einem sehr vernachlässigbaren Zusammenhang sprechen (Qui-Quadrat Test, X2= -0,051; X2= -0,000). Der Spearman-Rho Korrelationstest ergab auch bei den anderen Variablen keine nennenswerten Zusammenhänge. So korreliert Bettlägerigkeit weder mit der Körperstatur (rho= -0,004), der Aufenthaltsdauer (rho= 0,087) noch mit der PatientInnenzahl/Station (rho= 0,042). Auch die Korrelationstests zwischen Ortsfixierung und den untersuchten Einflussfaktoren kommen zu ähnlichen Ergebnissen. So beeinflussen weder die Körperstatur (rho=-0,004), die Aufenthaltsdauer (rho=0,094) noch die PatientInnenzahl/Station (rho= 0,003), die Entstehung von Ortsfixierung.

Einflussfaktor Einrichtung

Im Rahmen dieser Studie zeigte sich, dass die Bettlägerigkeits-, und Ortsfixierungszahlen zwischen den 12 untersuchten Einrichtungen teilweise sehr stark schwankten. So beträgt die Bettlägerigkeit zwischen 19,7% und 79,5%, die der Ortsfixierung zwischen 43,2% und 78,2%.

Um erste Erklärungen für diese starken Unterschiede (bei durchwegs ähnlichem Klientel und Personalstand) zu erhalten, wurden zusätzlich fünf ExpertInneninterviews mit PflegedienstleiterInnen der teilgenommenen Einrichtungen geführt.

Generelle Faktoren für eine zunehmende Mobilitätsbeeinträchtigung sehen die ExpertInnen im zunehmend schlechteren Allgemeinzustand der BewohnerInnen bei Heimeinzug, in medizinischen Faktoren wie Schmerz, Schwäche und Depression, aber auch in den oftmals nur mangelhaft vorgegebenen Zielvorgaben seitens der Leitung, die sich negativ auf die Mobilität der BewohnerInnen auswirken können. Auch Reuther *et al.* (2010) zeigten in ihrer Studie, dass die Bewegungsfähigkeit älterer HeimbewohnerInnen durch viele Krankheiten beeinflusst wird und sich auch auf das Bewegungspotential auswirken kann (Reuther *et al.*, 2010, 140-142). Auch "auslösende Momente" wie Krankenhausaufenthalte, der Heimeinzug selbst oder Stürze können die Mobilität der BewohnerInnen negativ beeinflussen (Zegelin, 2010, 115).

Mögliche Gründe für die unterschiedlichen Prozentwerte bei Bettlägerigkeit und Ortsfixierung zwischen den Einrichtungen sehen die befragten ExpertInnen einerseits in der Haltung bzw. Einstellung zur Mobilisation und andererseits in baulichen Strukturen und fehlenden Hilfsmitteln. Die Ansicht der ExpertInnen wird gestützt durch Studien, die aufzeigen, dass Pflegende oftmals die Mobilisierung der BewohnerInnen nicht als deren pflegerische Kernaufgabe ansehen, und dass bei der großen Arbeitsbelastung auf den Stationen oftmals zu wenig Zeit für die Förderung der Mobilität der HeimbewohnerInnen bleibt (Reuther *et al.*, 2010, 141; Zegelin, 2010, 129). Wie Zegelin (2010) aufzeigt werden zwar viele BewohnerInnen aus den Betten in Rollstühle mobilisiert, wodurch sie nicht mehr in die Kategorie der bettlägerigen Menschen fallen, trotzdem bleiben diese Menschen unbeweglich an einem Ort fixiert. Des Weiteren führt Zegelin (2010) an, dass durch diese passive Mobilisation zwar eine schwere Form der Bettlägerigkeit hinausgezögert werden kann, die Folgen der Ortsfixierung aber weiterhin eine sehr große Problematik darstellen. Da viele BewohnerInnen auf den Gebrauch eines Rollators oder eines Rollstuhls angewiesen sind, sollten diese Hilfsmittel auf die BewohnerInnen "zurechtgeschneidert" werden. Meist handelt es sich bei diesen Rollstühlen aber lediglich um gewöhnliche Transportrollstühle für kurze Strecken mit wenig Sitzkomfort und dünnen Polsterungen (Zegelin, 2010, 119).

Um Maßnahmen zur Verbesserung der Mobilität der BewohnerInnen anzudenken, ist es aus ExpertInnensicht vor allem notwendig, Anreize für Bewegung zu schaffen. Diese Konzepte sollten den Menschen mit seiner persönlichen Lebensbiographie erfassen und nicht alleine auf die physiologische Verbesserung seines Zustandes abzielen. Menschen bewegen sich intentional, müssen dabei also einen Sinn und Freude empfinden. Wichtig ist es, Möglichkeiten zu finden, die betroffenen BewohnerInnen wieder aus ihrer Starre und Apathie zu lösen, wie auch Reuther *et al.* (2010) aufzeigen. Die vorhandenen Bewegungskonzepte sind in der Regel für rüstige SeniorInnen ausgelegt, für die Gruppe der bettlägerigen und ortsfixierten Menschen bestehen noch unzureichende Angebote (Reuther, 2008, 55; Zegelin, 2010, 174).

Daneben nennen die befragten ExpertInnen die Förderung der MitarbeiterInnen und dahingehend auch ein verbessertes Zusammenspiel der Berufsgruppen als wesentliche Faktoren zur Verbesserung der Mobilität der BewohnerInnen. Dem Austausch pflegerelevanter Informationen in Teamsitzungen und eine Verbesserung der interdisziplinären Zusammenarbeit, insbesondere der Vernetzung mit Physiotherapie und Ergotherapie, werden auch in der Literatur in Verbindung mit Bewegungsförderung ein hoher Stellenwert eingeräumt (Reuther *et al.*, 2010, 141).

7 DISKUSSION DER ERGEBNISSE UND METHODE

Die erstmals vorliegenden Zahlen zur Prävalenz von Immobilität in der österreichischen Langzeitpflege machen auf die hohe Problematik von Ortsfixierung und Bettlägerigkeit aufmerksam und tragen zu einer Bewusstseinsbildung bei, diese Phänomene genauer in den Blick zu nehmen.

Es ist schwierig diese Zahlen zum gegenwärtigen Zeitpunkt in ein Verhältnis zu stellen, da bis dato keine Prävalenzzahlen zu Ortsfixierung und Bettlägerigkeit aus anderen Ländern vorliegen.

Einen möglichen Erklärungsansatz für die hohe Zahl der Betroffenen können die durchgeführten ExpertInneninterviews, in denen immer wieder auf einen schlechteren Allgemeinzustand (ab den Pflegegeldstufen 4 und 5) bei Aufnahme in die Einrichtungen hingewiesen wurde, liefern. Diese Pflegegeldstufen gelten üblicherweise dann, wenn der Pflegebedarf durchschnittlich länger als 180 Stunden pro Monat beträgt, eine weitgehende Immobilität besteht und ein außergewöhnlicher Pflegeaufwand erforderlich ist (Bundespflegegeldgesetz BPGG, 2012, §4). In diesem Zusammenhang zeigen aktuelle Zahlen, dass im Juli 2011 insgesamt 396.313 Personen Pflegegeld bezogen haben, wobei 88.301 Personen auf die Pflegegeldstufen 4 und 5 entfielen. Gegenüber dem Jahr 1999 (62.470 Personen) ist das eine

Steigerung um 41,3% (Statistik Austria, 2011). Der Anstieg pflegebedürftiger Menschen, die grundsätzliche Einschränkungen haben, lässt jedoch keine Aussagen über die Pflegequalität in den Einrichtungen zu.

Da es sich bei dieser Studie um eine Punktprävalenzerhebung - eine Momentaufnahme und damit Abbildung des Ist-Zustandes in den untersuchten Einrichtungen handelt, können Aussagen über Verläufe und Entwicklungen erst getätigt werden, wenn man diese in zukünftigen Studien betrachtet.

Die Beobachtung von Verläufen ist auch insofern als wichtig zu erachten, nachdem es sich, wie schon Zegelin aufzeigte (2010), bei einer zunehmenden Immobilisierung um ein Verlaufsgeschehen handelt. Um noch genauere Aufschlüsse über die Zustände der BewohnerInnen erhalten, scheinen regelmäßige Datensammlungen der Zustände der BewohnerInnen über eine längere Zeitspanne, und vor allem schon ab dem Zeitpunkt des Heimeinzuges sinnvoll. Diese ermöglichen den Nachvollzug des Allgemeinzustandes der BewohnerInnen bei der Aufnahme, bzw. zeigen die Zeitpunkte von Verschlechterungen oder Verbesserungen an. Für die Darstellung von Verläufen und Entwicklungen sind Längsschnittstudien im Sinne von Periodenprävalenzerhebungen ideal, bei denen die Datenerhebung zu verschiedenen Zeitpunkten erfolgt (Bartholomeyczik *et al.*, 2008, 85; Mayer, 2011, 130).

Die Gegenüberstellung der Ortsfixierungs-, und Bettlägerigkeitszahlen nach Einrichtungen lässt deutliche Schwankungen erkennen, die momentan zwar noch nicht eindeutig erklärbar sind, aber bereits auf die Existenz vielfältiger Einflussfaktoren hinweisen. Da weder die erhobenen körperbezogenen noch die rein organisationsbezogenen Faktoren, wie die Größe der Stationen oder die Aufenthaltsdauer, Rückschlüsse über Einflüsse zulassen, ist es in zukünftigen Studien wichtig auf die Suche nach einflussnehmenden Faktoren zu fokussieren.

Bei der Suche nach Einflussfaktoren sollte gerade auch der subjektiven Sichtweise von Betroffenen große Aufmerksamkeit geschenkt werden, da schon Zegelin darauf hinweist, dass potentielle Einflussfaktoren sowohl bei den Betroffenen selber, als auch von deren Umfeld abhängig sind (Zegelin, 2010, 159). Um das persönliche Erleben und das subjektive Krankheitserleben der Betroffenen in Erfahrung zu bringen, würden sich vor allem qualitative Forschungsansätze eignen, die den Menschen in seiner Ganzheitlichkeit berücksichtigen. Zur Verbesserung ihrer Lebensqualität und der Wirkungsweise von therapeutischen Interventionen, zur Vermeidung bzw. Prävention der Phänomene Bettlägerigkeit und Ortsfixierung sind neben dem Wissen um die Zahl der Betroffenen auch das Verstehen derer subjektiven Werte und Erfahrungen unumgänglich (Mayer, 2011, 118).

Alle beschriebenen Ergebnisse können als Grundlage für weitere Untersuchungen einbezogen werden, um Interventionen gegen Ortsfixierung und Bettlägerigkeit und die daraus resultierende Pflegebedürftigkeit zu entwickeln und um die Qualität der Pflege in Bezug auf die Vermeidung von Ortsfixierung und Bettlägerigkeit verbessern zu können.

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USE OF OREM'S SELF-CARE DEFICIT NURSING THEORY IN THE SELF-MANAGEMENT EDUCATION OF PATIENTS WITH TYPE 2 DIABETES

A CASE STUDY

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ABSTRACT

Nursing theories guide the practices of the care process. In this study, it was thought that Orem's self-care deficit nursing theory (SCDNT) could be a useful guide in diabetes self-management education to improve the self-care behavior of a diabetes patient, and an attempt was made at indicating its applied use. We recommend that use of the SCDNT in diabetes self-management education be practised in a randomized controlled trial.

KEYWORDS

diabetes education, self-care deficit nursing theory, type 2 diabetes

1 INTRODUCTION

Diabetes is a chronic and metabolic disease characterized by macrovascular and microvascular complications along with the dysfunction of fat and protein metabolisms as a result of complete or partial deficiency of insulin secretion or insulin resistance at different levels (American Diabetes Association [ADA], 2012). Type II diabetes constitutes almost 80-90% of all diabetes cases (World Health Organization [WHO], 2011). It has an increasing prevalence due to sedentary lifestyles and changes in forms of nutrition (WHO, 2011). In Turkey, while the prevalence of diabetes was found to be 7.2% in a study conducted by Satman et al. in 2002 among adults aged 20 and over, this ratio increased to 13.7% in 2010.

Uncontrolled blood glucose level is the basic problem in individuals with diabetes. Elevated blood glucose level leads to cardiovascular diseases, nephropathy, neuropathy, lower extremity diseases, amputations and visual impairment (WHO, 2011). In diabetes management, the aim is to ensure glycemic control and prevent complications (ADA, 2012). The treatment recommended in the 2012 clinical guide of American Diabetes Association to ensure glycemic control and prevent complications in diabetes patients includes medical nutrition treatment, physical activity, oral antidiabetic/insulin treatment, self blood-glucose monitoring and diabetes self-management education (ADA, 2012). According to Orem's self-care deficit nursing theory (SCDNT) (Orem, 1995), the clinical guidance of ADA (2012) suggests attending to health deviation self-care requisites. So the person with diabetes needs to re-regulate medical nutrition treatment and physical activity, if necessary, using drug and blood-glucose monitoring to evaluate the outcome of self-care activities. The person with diabetes must learn how to evaluate themselves, decide what actions need to be taken to attend to their needs, and perform those actions; and these actions will become possible with education about diabetes.

Diabetes self-management education is the process of informing, strengthening and empowering the diabetes patient for diabetes self-care (IDF, 2009). It is recommended that diabetes self-management education should be provided based on a theoretical approach (AADE, 2010). In this study, diabetes self-management education was provided based on self-care deficit nursing theory.

When the studies in which the application of Orem's SCDNT to diabetes patients is observed, the studies done have been descriptive, for the most part. In these studies, generally the self-care agency and the factors that have an influence on self-care have been analyzed. If we are to observe studies related to how the theory is used, only one experimental (Ünsal and Kızılcı, 2011) and two case studies (Kumar, 2007; Clark, 1986) can be found in the literature. In these case studies, diagnoses were established in line with the self-care deficit nursing theory but it was not clear how the nursing planning and implementation were carried out. In this study, diagnosis, planning and practice were also carried out in line with the self-care deficit theory of nursing. Differently than in the other two studies, it was explained how nursing practices were planned and conducted in line with the self-care deficit theory of nursing. Diabetes self-management education was applied in this study. The objective of this study is to indicate the use of SCDNT in the diabetes self-management education of patients with Type II diabetes.

2 RESEARCH METHODOLOGY

This study is a descriptive case study. The selected subject was a female patient who resorted to the Diabetes Education Center affiliated to the Directorate of Nursing Services of Dokuz Eylül University, and was subsequently followed up for three months. The case study was approved by the Ethics Committee of Non-Invasive Research at Dokuz Eylul University. We used her case for the study with her written and oral permission. According to AADE, diabetes self-management education is a problem-solving process and consists of such steps as assessment (process identification), goal setting, planning, implementation and evaluation (AADE, 2010). These steps are the same as in the nursing process. In this study, the five steps of DSME were used and five steps were implemented at each session held with the patient.

3 USE OF SELF-CARE DEFICIT NURSING THEORY IN DIABETES SELF MANAGEMENT EDUCATION

Use of SCDNT in diabetes self-management education was shown in the course of assessment (process identification), goal setting, planning, implementation and evaluation steps.

Assessment (22nd February / 01st March / 05th April / 05th May, 2011): Orem stated that it is necessary to identify the basic conditioning factors (BCFs) of the individual and the relationship between the status of meeting the therapeutic self-care requisites and self-care agency for a nursing diagnosis (Figure 1) (Orem, 1995). The purpose of diagnosis is to determine self-care deficits and the reasons for them. To this end, the patient's BCFs (Table 1) were identified and then the status of meeting therapeutic self-care demands (Table 2) and self-care agency was assessed. The patient's self-care agency was determined by assessing the power components of self-care agency, and it was concluded that there was a knowledge deficit concerning diabetes management; patients did not believe their health status could be improved and some disorders were ignored.

The patient could meet her universal and developmental self-care demands on her own. However, some deficits were detected in such fields as being aware of and prepared for the effects and results of pathological conditions, effective implementation of medically prescribed diagnostic, therapeutic, and rehabilitative measures, and being aware of and prepared for the effects of medical care (Table 2).

When the relationship between the patient's BCFs, and therapeutic self-care requisites and self-care agency was examined (Figure 1), self-care deficits were determined to be: deficiency in the awareness of effects and results of the pathological condition, lack of knowledge and a consequent disbelief that their health status could be improved; deficiency in the effective implementation of medical treatments and rehabilitative interventions due to ignoring some disorders in the belief that they will recover in time, and deficiency in awareness of the effects of medical care (Table 2).

Goal setting (22nd February / 01st March / 05th April / 05th May, 2011): Involvement of the person with diabetes in the research process is critical for achievement of goals. At each session, goals concerning three self-care deficits, and method(s) to achieve these goals, were determined together with the patient (Table 3).

Planning (22nd February / 01st March / 05th April / 05th May, 2011): This is the process of determining how to develop self-care agency or dependent care agency in order to meet the therapeutic self-care requisites of the individual. The questions to be resolved are who will meet the individual's therapeutic self-care requisites (self-care agent, dependent care agent) and how will they be met (nursing system) (Orem, 1995). It was decided that the patient could be her own self-care agent while a supportive-educative nursing system should be used to develop her skill in meeting the self-care requisites (Table 3).

Implementation (22nd February / 01st March / 05th April / 05th May, 2011): According to Orem, this process is implementation of the actions organized and planned by nurses in the nursing-planning process to develop the self-care agency or dependent-care agency with the aim of meeting the therapeutic self-care demands of individuals (Orem, 1995). Diabetes self-management education was applied in the supportive-educative system (Table 3). Diabetes self-management education was completed in four sessions. Each session was composed of five steps. The first step is assessment; the second step is goal-setting; the third step includes planning, the fourth step is implementation, last and the fifth step is evaluation (AADE, 2010). At each session, fives steps of self-management education were implemented (Figure 2). Therefore at each session, a different topic of diabetes self-management education was discussed (Figure 2).

Each session lasted for about one hour. At each session, a knowledge deficit of the patient was satisfied, the patient's experiences regarding diabetes, its treatment and the results were discussed, goals were set and consideration was given to whether the goals set for the following session would be fulfilled or not. Goals which were set but could not be fulfilled were addressed at each session, the reasons for failure were interrogated and discussed with the patient, and these goals were revised. During this time, the patient received telephone consultancy three times with regard to hyperglycemia and the use of complementary and alternative treatments.

Evaluation (22nd February / 01st March / 05th April / 05th May, 2011): According to Orem, the individual's status in meeting his or her own self-care demands and in developing self-care agency/dependent care agency are assessed in the nursing assessment process (Orem, 1995). With this point of view, the patient's behaviours concerning diabetes management and status of accomplishing the objectives were discussed individually during each interview with the patient, according to the information obtained; the patient's assessment results are given under three groups below, in relation to the determined self-care deficits.

Being aware of and prepared for effects and results of pathological conditions: After consultancy, diabetes self-management education and discussions, the patient managed to express what HbA1c and lipid profiles were and to summarize the complications caused by changes in the lipid profile and overweight. She could interpret her own laboratory results and reported by telephone the values that she got three months later.

Effective implementation of medically prescribed diagnostic, therapeutic and rehabilitative measures: She stated that she postponed the plan for 30-minutes daily activity due to influenza but would start walking after dinner when the weather warmed up. It was observed that the patient sent to the dietician after the first interview went to the dietician. She stated that she tried to comply with the snacks and the diet plan recommended by the dietician. She also stated that she carried out site control prior to injection, started to use a 6 mm needle, grabbed the skin properly during injection, began to use her arms as a place of injection but did not use her legs as she felt pain there after an injection. It was also observed that the patient sent to the diabetic foot polyclinic went to the polyclinic. She started to perform a daily foot examination, cut her nails properly, wears orthopedic shoes and cotton socks, and stopped wearing flip-flops. Furthermore, she began to perform the blood glucose measurement as recommended and record it. She stated that she applied the insulin doses recommended by the doctor in time.

She could explain how she could manage hypoglycemia. In the event of hyperglycemia, she increased the insulin dose for two units, reduced the carbohydrate intake and monitored the blood glucose level. She also stated that she would resort to a health institution if she could not manage any case of hypoglycemia and hyperglycemia.

She realized the importance of having her feet and eyes examined annually, taking the kidney function tests annually and taking the lipid control and HbA1c monitoring once every three months. In the interview after three months, she had had her HbA1c and lipid levels and blood pressure measured, and showed them to us.

Positive developments in the patient's health, positive results of the objectives which were set and applied per week and her weight, HbA1c and lipid values in the first interview and those obtained after three months were shared with the patient (Table 4). It was observed that she was rather pleased and motivated.

Being aware of and prepared for effects of medical care: The patient could explain the risks of hypoglycemia, hyperglycemia and lipohypertrophy that may develop depending on insulin treatment mistakes.

4 CONCLUSION AND FURTHER RESEARCH

Use of SCDNT in diabetes self-management education served as a guide in identification, planning and implementation. In the course of identification, a wide perspective was provided by determining the existing problems and which problems may occur in the patient's self-care attitude. Her self-care behavior has provided a wide range in evaluating the basic conditioning factors which influence the self-care and in the inspection of the environment. Nursing planning, has been guided by the self-care agency of the patient who is supposed to take care of her requisites and how the responsible person can help her by means of nursing systems. The implementation has demonstrated what can be done to improve self-care behaviors and how to address the subject (education, guide etc.). Therefore, it increased the patient's involvement in her own care and brought positive changes to her health status.

We had difficulty in putting the theory into practice due to the abstract nature of its concepts (power components of self-care agency, therapeutic self-care demands, human and health state concept).

We recommend that the use of self-care deficit nursing theory in diabetes self-management education be practised in a randomized controlled trial.

Figure 1. Conceptual Structure of the Self-Care Deficit Nursing Theory

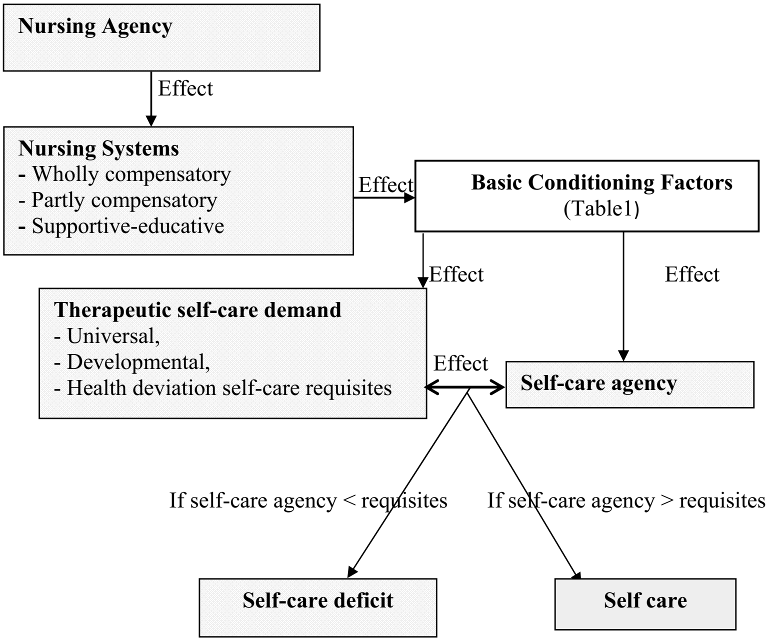

Figure 2. Process of Diabetes Self-Management Education in the Supportive-Educative System

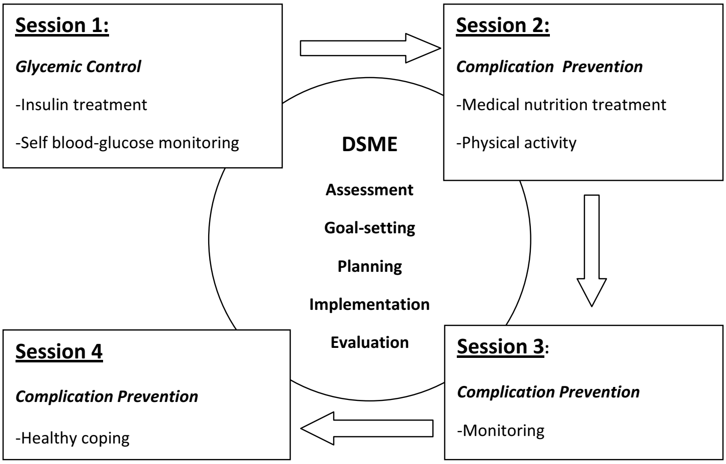

Table 1. Basic Conditioning Factors of the Patient

1. Age	66
2. Gender	Woman
3. Developmental State	Older
4. Health State	Type II diabetes for 17 years, **Laboratory values (22 February 2011):** Glycosylated hemoglobin (HbA1c): 10,2, Fasting blood sugar (FBS): 239 mg/dl, Postprandial glucose (PBG): 297 mg/dl, High-density lipoprotein (HDL): 39 mg/dl, Low-density lipoprotein (LDL): 181 mg/dl, Total cholesterol: 244 mg/dl, Triglyceride: 122 mg/dl, Blood pressure (BP):160/80mmHg, **Complications:** No retinopathy, nephropathy and neuropathy but uses glasses due to astigmatism, **Other disease:** Hypothyroidism, hypertension, hyperlipidemia. **Medicines:** Insulin aspart 16 units, insulin detemir 46 units, incuria, levothyroxine sodium and losartan potassium 100 mg, hydrochlorothiazide 25 mg. **Health perception:** Health state was described as mediocre.
5. Sociocultural Orientation	High school graduate, retired from topograhy 29 years ago, not working in any job now. In addition to the medicines prescribed by the doctor, she consumed herbal teas (lime, cinnamon, carnation, sage tea, ginger, menthol).
6. Health Care System Factors	Affiliated to the social security institution. She stated that she used the university hospitals, family health centres and state hospitals for health checks.
7. Family System Factors	Widow and had one child. She lived alone.
8. Pattern of Living	She did not use cigarettes and alcohol. She attended a needlecraft course as a hobby and states that she did no physical activity except for shopping and housework.
9. Environmental Factors	She lived on the sixth floor of an apartment building with an elevator. Building had a green space and a walkway around it for physical activity.
10. Resource Availability and Adequacy	She stated that she could find the medicines and materials necessary for her treatment easily (insulin, needle etc.) but had difficulty in getting appointments for routine controls, She could receive advice from nurses when it was required/needed

Table 2. The Patient's Therapeutic Self-Care Demands and Self-Care Deficits

Universal Self-Care Requisites and Self-Care Deficit	
1. Air	No problem
2. Water	No problem
3. Food	No problem
4. Excretion processes	No problem
5. Activity- Rest	No problem
6. Social Interaction	Lives alone and thinks that her sister could help when she needed. She attended the needlecraft course as a hobby.
7. Prevention of Hazards	No visual, hearing or physical impairment that will cause danger. Uses glasses due to astigmatism.
8. Promotion of normalcy	States that there was not a situation where she could not do something due to the disease even though she wanted to.
Developmental Self-Care Requisites and Self-Care Deficit	
1. Protecting and maintaining the developmental environment	She presented for mammography once every two years. She is a wise woman.
Health Deviation Self-Care Requisites and Self-Care Deficit	
1. Seeking and securing appropriate medical assistance	When she got ill, she resorted to institutions where internal-diseases or endocrine experts work for treatment and checks. No problem.
2. Being aware of and prepared for effects and results of pathological conditions	She knew neither HbA1c and lipid profile nor the complications to be caused by high HbA1c, changes in the lipid profile (triglyceride, LDL and reduction in the total cholesterol level and increase in HDL cholesterol) and overweight. **Self-care deficit:** Insufficient awareness of effects and results of pathological condition due to lack of knowledge.
3. Effective implementation of medically prescribed diagnostic, therapeutic, and rehabilitative measure	Did not perform physical activities regularly. She sometimes walked in the morning when she was hungry. She did not apply the diabetic diet plan and did not eat snacks. She did not conduct the injection site control, did not payimportance to the insulin dose and distance between two injections, used only the umbilicus and around it as insulin injection site, performed injection with an injector of 8 mm without grabbing the skin at 90 C (Body Mass Index (BMI): 41.4).

Table 2. The Patient's Therapeutic Self-Care Demands and Self-Care Deficits

	She did not perform the daily foot examination, did not cut her nails properly, did not wear orthopedic shoes and cotton socks but wore flip-flops. She performed the self blood-glucose measurement at random. She stated that she slept when her blood glucose was below 70 mg/dl after eating a piece of bread and did not measure her blood glucose for control, and ate something when her postprandial blood glucose was above 200. She had never taken the foot examination, took the eye examination and kidney function tests at random and took the lipid control and HbA1c follow-up once every six months. She measured her blood pressure when she felt unwell in herself. **Self-care deficit:** Insufficiently effective handling of medical treatments and rehabilitative interventions due to lack of knowledge, disbelief that her health could improve, ignoring some disorders and the belief that these disorders will fade away on their own.
4. Being aware of and prepared for effects of medical care	She did not know the risks of developing hypoglycemia, hyperglycemia and lipohypertrophy depending on insulin treatment mistakes. **Self-care deficit:** Insufficient awareness of the effects of medical care due to lack of knowledge.
5. Modifying the self-concept and self image in a particular state of health	No problem.
6. Learning to live with effects of pathological conditions	She was not problematic with her diabetes and overweight and tried to manipulate her diabetes. No problem.

Table 3. Nursing Interventions Planned and Implemented to Improve Patient's Self-Care Deficit

Self-Care Deficits	**Goals** (Goals were determined according to ADA 2012)	**Supportive-Educative Nursing Implemention for the Patient**
1. Insufficient awareness of the effects and results of the pathological condition due to lack of knowledge	1. Explaining the concept of HbA1c, 2. Explaining what the lipid profile is, 3. Knowing the complications that may be provoked by high level of HbA1c 4. Knowing the complications that may be provoked by changes in the lipid profile 5. Knowing the complications that may be induced by overweight	1. Information was provided about what the HbA1c and lipid profile were, and the complications caused by a high level of HbA1c, changes in the lipid profile and overweight. 2. Effects, reasons and results of high levels of HbA1c and lipid values were discussed with the patient on the basis of her laboratory results.
2. Insufficiently effective handling of medical treatments and rehabilitative interventions due to lack of knowledge, disbelief that her health will improve, ignoring some disorders and the belief that these disorders will fade away on their own	1. Performing physical activity regularly, 2. Starting this physical activity one hour after the meal, 3. Eating the recommended main meals and snacks, 4. Applying the insulin at the right dose, conducting the injection site control 5. Conducting the site rotation and in-site rotation per week, 6. Using a 6 mm needle, grabbing the skin during injection, 7. Performing a daily foot examination, 8. Cutting the nails properly,	1. Information was provided as to how to perform regular physical activity, the importance of complying with the medical nutrition therapy and medicine therapy, how to conduct the foot care, and the importance of self-monitoring. 2. Patient was trained about the foot and eye examinations that should be done routinely, kidney function tests, lipid and HbA1c controls, and the importance and frequency of blood pressure monitoring.

Table 3. Nursing Interventions Planned and Implemented to Improve Patient's Self-Care Deficit

	10. Performing the self blood glucose measurement as recommended. 11. Performing her eyes and feet examined annually, taking the kidney tests annually, conducting the lipid control and HbA1c follow-up once in every three months.	3. Brochures were given to inform her regarding foot care and management of hypoglycemia and about the frequencies and aims of controls that should be conducted routinely. 4. Patient was sent to the dietician and the diabetic foot polyclinic. 5. Positive development in the health of the patient as a result of the interventions performed in line with the weekly objectives and the comparison between HbA1c and lipid levels of the first month and those of the third month were explained to the patient. Positive development in her health promoted her belief that her health could change for the better. 6. Importance of resorting to a doctor when making health-related changes was explained.
3. Insufficient awareness of the effects of medical care due to lack of knowledge	Explaining the hypoglycemia, hyperglycemia and lipohypertrophy that may develop depending on insulin treatment mistakes	1. Patient was informed about the possible problems related to the treatment (hypoglycemia, hyperglycemia and lipohypertrophy). 2. Individual training; inspection and palpation method was indicated and the patient was made to perform it in order to identify hypertrophy.

Table 4. Health results obtained in the first and last interviews with the patient

	First interview (22 February 2011)	Last interview (05 May 2011)
HbA1c	10.2	9.4
HDL	39	43 mg/dl
LDL	181	76 mg/dl
T. Chol.	244	138 mg/dl
Trig.	122	94 mg/dl
Blood pressure	160/85	145/85 mmHg

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SPIRITUALITY SELF-CARE EFFECTS ON QUALITY OF LIFE FOR PATIENTS DIAGNOSED WITH CHRONIC ILLNESS

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ABSTRACT

This study extended Orem's Self-Care Deficit Nursing Theory (SCDNT) by including the specific construct of spiritual self-care practices. This research is part of a larger study that examined relationships between quality of life and spirituality, spiritual self-care practices, chronic illness self-care for heart failure, and physical and mental health. Based on an extensive literature review, practice experience, and a discovery theory-building approach, a mid-range theory, White's theory of spirituality and spiritual self-care (WTSSSC), was developed. To test this mid-range theory, empirical indices of many concepts were identified from prior studies and one new instrument (the Spiritual Self-Care Practice Scale) was developed. The larger study examined hypothesized relationships among the concepts of the mid-range theory in a sample of 142 urban African American outpatients diagnosed with heart failure. Results of this study provided support that the WTSSSC is a viable extension of Orem's SCDNT. The present study examined spiritual self-care practices as a mediator in the relationship between chronic disease (heart failure) and overall QOL for African Americans. Results of this study provided support that spiritual self-care practices helped manage chronic illness, specifically heart failure and quality of life. Nurses who work with patients diagnosed with heart failure should provide instruction on self-care practices, specifically for heart failure, and encourage the use of spiritual self-care practices to enhance well-being and QOL. Nursing education needs to include the importance of spiritual self-care practices as part of teaching Orem's theory of self-care to enhance patient health and QOL. This education could be presented in nursing education classes in colleges and universities; professional development programs; and presentations at state, regional, national and international conferences. Further research is needed to continue development of the WTSSSC.

KEYWORDS

chronic illness, quality of life, self-care, spiritual self-care, spirituality

1 INTRODUCTION

Understanding the ways in which spiritual self-care influence health and wellbeing outcomes requires an understanding of the nature of self-care. The purpose of this paper is to examine the integration of heart care self-care and spiritual self-care practices as enhancements to Orem's self-care deficit nursing theory (SCDNT), with research and practice applicability. Increased clarity of the role of spirituality in self-care practices is needed to understand how spiritual practices, specifically self-care, can help maintain health.

The relationship between spirituality and health-related quality of life (QOL) has been a major focus of study for the last few years. Research on spirituality has been published in diverse disciplines, including theology, sociology, psychology, and medicine, with these studies contributing to the continued discussion on this construct (Como, 2007). An important element in the lives of many African Americans, who are living with chronic illness, is spirituality.

Chronic illness is understood as "the medical condition or health problem with symptoms or limitations that require long-term management" (Frietas and Mendes, 2007, 592). It involves permanence and a deviation from normalcy, affecting aspects of everyday life, including physical, psychological, and social abilities. Some chronic illnesses can be controlled through diet, exercise, and certain medications. Studies have shown that people with chronic illnesses are more likely to engage in spiritual self-care practices to help cope with their situations (Polzer, 2007; Samuel-Hodge *et al.*, 2000).

One chronic illness overlooked in research on African Americans is heart failure (HF). A recent search on the Cumulative Index to Nursing & Allied Health Literature (CINAHL™) yielded no published papers on the role of spirituality and self-care practices among African-Americans with HF. Statistics regarding HF are readily available. For example, in 2005 the prevalence for HF in adults age 20 and over was 5,300,000, with about half of the incidence involving women (American Heart Association [AHA], 2008). African Americans have a higher incidence of HF, develop HF at an earlier age, and experience higher rates of mortality related to HF than Caucasians. The health disparities for African American men and women with HF are clearly demonstrated in statistics reflecting excess morbidity and mortality. In the U.S., approximately 4.2% of the African American women, compared to 1.8% of Caucasian women, are living with HF (AHA 2009a, b, c). Total mention death rate for heart failure (HF listed on a death certificate as either the cause of death or a contributing factor) is highest for African American men (81.9 per 100,000 deaths) followed by Caucasian men (62.1 per 100,000). The African American female death rate for HF (58.7) is 15 points higher than for Caucasian women (43.2; AHA, 2009a, b, c). The estimated financial cost of HF in the United States in 2008 was $34.8 billion.

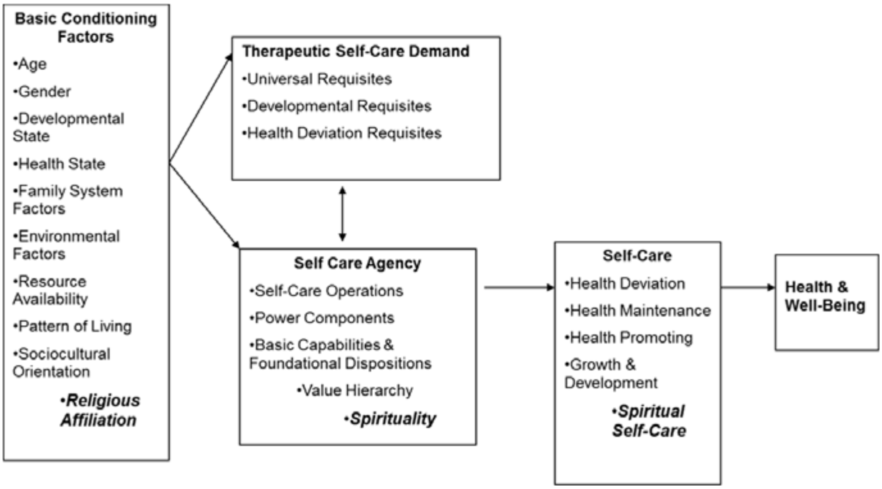
To further nursing science and practice concerning this topic, the intent of this research was to understand how participation in spiritual self-care practices helps African-American men and women with a diagnosis of HF practice self-care that can influence their QOL. The hypothesis tested for this study is: Levels of spiritual self-care practices will mediate the relationship between heart failure self-care practices and quality of life among African American men and women who are being treated for HF.

A correlational research design with a sample that included 142 African American patients diagnosed with heart failure was used to determine if spiritual self-care practices were mediating the relationship between heart failure self-care practices and quality of life. The researcher met with patients individually at two outpatient clinics to complete the instruments for the study. Data analysis was completed using regression methods and following the procedures for mediation as outlined by Baron and Kenny (2012).

The study was limited to African American patients diagnosed with heart failure. Holt, Lukwago, and Kreuter (2003) observed that African Americans in their study reported relying on God to do what physicians or modern medicine cannot; working together with God for good health; and being empowered by their religion to take care of themselves.

According to Orem (2001), self-care is an important component of treatment for chronic illness. Self-care embodies the whole patient, physically, mentally, and emotionally. Expanding Orem's SCDNT to include spiritual self-care as a contributing factor in QOL is important in the treatment of chronic illness, specifically HF (See Figure 1). Understanding patients' perceptions of the role of spiritual self-care practices in managing their chronic illness, specifically HF, nursing plans can be developed that incorporate spiritual self-care. Medical professionals need to recognize the role of spirituality in helping patients cope with their chronic illness. The study also contributes to the development of nursing science by explaining concepts of spirituality and spiritual self-care within an extant nursing theory. Nurses can use the findings to guide them in assessing and intervening to meet the spiritual needs of patients. Exploring the relationship between heart failure self-care practices, spirituality self-care practices, and QOL outcomes provides new insights into holistic care for patients with chronic illness.

Figure 1. SCDNT with spirituality and related constructs added



2 LITERATURE REVIEW

2.1 Orem Self-Care Deficit Nursing Theory

Orem's SCDNT is an appropriate framework for patients with chronic illnesses. While Orem includes spiritual experiences as an element of well-being, the construct of *spirituality*, essential to the human experience, has not been investigated within the SCDNT. Spiritual self-care is defined as the set of spiritually-based practices in which people engage to promote continued personal development and well-being in times of health and illness. This study focused on heart failure self-care practices, a type of health deviation self-care practices, and spirituality self-care effects on quality of life.

Understanding the ways in which spirituality and spiritual self-care influence health and wellbeing outcomes requires an understanding of the nature of self-care. Increased clarity of the role of spirituality in self-care practices is needed to understand how spiritual practices, specifically self-care, can help maintain health. *Spiritual self-care* as a specific type of self-care activity should be a focus of nursing theory development and research.

The power to engage in self-care is called *self-care agency*. Within the SCDNT, self-care agency (SCA) is defined as "the complex acquired ability of mature and maturing persons to know and meet their continuing requirements for deliberate, purposive action to regulate their own human functioning and development" (Orem, 2001, 254). SCA encompasses the capacity of individuals to engage in practices and behaviors to care for themselves. *Ability* allows individuals to acquire knowledge of appropriate courses of actions, decide what actions to take, and act to achieve change.

Self-care agency can be described as a three-part structure (Orem, 2001). One part of the structure consists of foundational capabilities and dispositions (FCDs). Another is the set of 10 power components enabling performance of self-care operations. The third is the operations needed for self-care. Each of these elements can be enhanced by the addition of spirituality and spiritual self-care practices.

2.2 Spirtuality

Carson and Koenig (2008) have noted that spirituality is a construct that has three interrelated meanings in nursing. These meanings, spiritual distress, spiritual needs, and spiritual well-being, are important for health promotion and health recovery. Fosarelli (2008) asserted that the lives of healthy people could be enhanced by spirituality that gives meaning to their lives and provide comfort in difficult times. Spirituality helps support and sustains a positive outlook. Spirituality can provide people who are having chronic health problems with peacefulness, reasons for living, a sense of purpose, and a sense of harmony (Katerndahl, 2008). Increased spirituality and spiritual support can be important coping mechanisms for individuals who are ill or dying (Creel and Tillman, 2008). Spirituality helps people with chronic conditions to accept their illnesses and live meaningful lives despite their health challenges (Sorajjakool *et al.*, 2006). Nurses need to understand how spirituality is manifested and use research to learn how to use spiritual interventions effectively when providing nursing support to people both in times of health and illness. Expanding Orem's self-care deficit nursing theory (SCDNT) to include spirituality and spiritual self-care practices can give nurses a framework that provides a holistic approach when attending to the healthcare needs of patients with chronic illnesses and their families.

While a common definition of spirituality has not been found, three common themes have emerged in the literature:(a) relationships with others; (b) acknowledgement of the existence of a higher being; and (c) appreciation for the greater world. The theme of relationships with others is includes accepting others, even when the things they do are wrong (McCauley *et al.*, 2008); interacting with people (Cooper *et al.*, 2001); and seeking forgiveness (Blumenthal, *et al.*, 2007). Acknowledgement of the existence of a higher being, (e.g. God, Allah, Waheguru, Vishnu, or Shiva; Musgrave *et al.*, 2002) is illustrated by feeling God's presence (Mofidi *et al.*, 2007); thinking that a higher power cares for oneself (Simoni and Ortiz, 2003); and believing that God can help people who have suffered from injuries or illnesses (Gonnerman *et al.*, 2008). The theme of the connectedness of spirituality to the broader world is demonstrated by being in touch with self, others, nature and the world (Dessio *et al.*, 2004); reflecting on the beauty of creation (McCauley *et al.*, 2008); enjoying change (Craig *et al.*, 2006; Runquist and Reed, 2007) and accepting that an individual is a part of a larger community (Daaleman *et al.*, 2001). After reviewing these common themes, spirituality for the purpose of this paper is defined as the subjective sense of existential connectedness including beliefs that reflect relationships to others, acknowledge a higher power, recognize an individual's place in the world, and lead to spiritual practices. (White *et al.* 2011, 50)

2.3 Quality of Life

Quality of life (QOL) is an individually defined and perceived state of well-being. The World Health Organization's [WHO], definition of QOL "an individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards, and concerns" (WHOQOL, 1994, 28) is used for this study. QOL is a construct that often is used in research on chronic illness. Ratings of QOL within the context of a chronic illness often depend on subjective responses to the changes produced by the disease (McMahon, 2002). QOL is a multidimensional concept that encompasses physical, emotional, and social effects on the individual's perception of daily life. For the purpose of the present study, QOL is being used as a holistic construct measuring well-being.

2.4 Chronic Illness and Self-Care Practices

Chronic illness is defined as "the medical condition or health problem with symptoms or limitations that require long-term management" (Frietas and Mendes, 2007, 592) and implies permanence and a deviation from normalcy that affect aspects of everyday life, including physical, psychological, and social abilities. According to Finseth (2009), a chronic illness typically lasts for longer than three months.

Self-care for chronic illnesses has been defined as "those activities that persons engage to manage ongoing limitations in structural or functional integrity. Chronic illness self- care focuses on meeting health-deviation requisites in addition to universal and developmental requisites" (Frietas and Mendes, 2007, 592). These behaviors could include: following up with medical care, self-monitoring (e.g., glucose checks for diabetes, blood pressure readings for hypertension), taking medications properly, adhering to diet and exercise regimens, and smoking cessation (Katon and Ciechanowski, 2002). Activities also may include seeking information regarding the chronic illness either through media sources, friends, or family; and self-advocacy either with medical professionals or family members (Loeb, 2006). Some goals of self-care are to control the disease progression, avoid hospital admissions, and have an improved QOL.

Self-care in HF is the primary basis of treatment. For chronically ill HF patients, self-care can seem overwhelming and all consuming. For most patients with HF, health care practitioners (HCPs) routinely advise patients about obtaining daily weights, monitoring swelling, taking medications, eating a low-sodium diet, obtaining routine vaccinations (e.g., yearly flu vaccine), exercising daily, and seeing their HCP regularly. However, research is needed to determine if these actions achieve the goals of improved QOL, better overall health, and reduced hospital admissions. The Heart Failure Society of America (2006) listed six specific recommendations with regard to educating and counseling in their Comprehensive Heart Failure Practice Guideline. The recommendations are:

1. Patients and family members receive individualized counseling and education that emphasizes self-care;
2. Patient's literacy levels, cognitive status, psychological state, culture, and access to social and financial resources be taken into account for optimal education and counseling;
3. Educational sessions begin with a thorough assessment of current knowledge of HF and issues that patients want to learn, and patients' perceived barriers to change;
4. Frequency and intensity of patient education and counseling vary according to the stage of illness;
5. Patients, during the care process, should be asked to demonstrate the self-care tasks being asked of him/her;
6. Essential education is provided during acute care hospitalization periods with the goal of assisting patients to understand the disease process and goals of treatment.

These lessons are then followed by step-by-step re-education and counseling at and after discharge and reinforced every one to two weeks for three to six months after discharge, with reassessment occurring periodically. These practice guidelines guided instrument development.

2.5 Spiritual Self-care Practices

Spiritual self-care is defined as the set of spirituality-based practices in which people engage to promote continued personal development and well-being in times of health and illness. Spiritual self-care focuses on meeting developmental requisites. Spiritual self-care is based on an individual's mind/spirit/body connection, upbringing, moral and religious background, and life experiences that originate from faith, feelings, and emotions. Examples of spiritual self-care can include building social networks or volunteering (Liu *et al.*, 2008); listening to inspirational music (Stake-Nilsson *et al.*, 2009); meditation (Delaney, 2005); and developing a sense of inner peace and quiet (Kreitzer *et al.*, 2009). Other examples of spiritual self-care include practicing yoga or Tai Chi, attending religious services, reading sacred or inspirational texts, prayer or mediation, hiking, walking or otherwise enjoying nature, and developing or mending personal relationships. Whatever the spiritual self-care activity, the goal is the enhancement of spiritual well-being and overall health and well-being.

3 RESEARCH METHODOLOGY

3.1 Research Design

A nonexperimental, correlational research design was used in this study. This research design was appropriate as the independent variable was not manipulated and no treatment or intervention was provided for the participants. A correlational research design is used to examine relationships among variables. Prior to collecting data, institutional review board (IRB) approval was obtained from the hospital where the data were collected and the university where the study was completed.

3.2 Participants

The participants in this study were African American patients diagnosed with heart failure who were being treated in two outpatient clinics associated with a large medical center in a major urban area. The inclusion criteria was: (a) African Americans who self-identify as members of this race, (b) diagnosed with HF by health care providers, (c) live in a large metropolitan area located in the southeastern section of Michigan, and (d) at least 18 years of age. The exclusion criteria were having a dual diagnosis of dementia or Alzheimer's disease as these individuals may not be able to respond accurately to the items on the survey.

A purposive sample of 142 participants who met the inclusion criteria was included in this study. The researcher met with potential participants at their appointments with their cardiologists. The patients completed the surveys at their appointments and received a stipend of $20.00 for their participation. Approximately 20 patients who were approached refused to participate because of time constraints.

In the larger study, using G-Power 3.1.0 (Faul *et al.*, 2007), a power analysis was completed to determine the appropriate sample size. Using an alpha level of 0.05, a moderate effect size of 0.15, and a two-tailed test, a sample of 142 provided a power of 0.95 for a multiple linear regression analysis with nine independent variables and the dependent variable, quality of life.

The mean age of the African American participants was 56.82 (*SD*=14.41) years, with a range from 18 to 91 years. An equal number of male and female participants (*N*=71) were included in the sample. The largest group of participants was single and had high school educations. Most of the participants were either retired or disabled. The participants had all been diagnosed with heart failure and were at either Stage C (*N*=50, 35.2%) or Stage D (*N*=67, 47.2%) of the disease. In contrast to their diagnosis, they generally reported their physical activities were either not limited (*N*=22, 15.5%) or somewhat limited (*N*= 62, 43.7%). They self-reported their physical health as either good (*N*=51, 35.9%) or fair (*N*=64, 45.1%) and their mental health as either good (*N*=64, 45.1%) or fair (*N*=55, 38.7%). Most of the participants indicated they were attending religious services at the time of the study (*N*=105, 75.0%) and practiced specific traditions related to spiritual beliefs (*N*=122, 86.5%). (See Table 1)

Table 1. Demographic Characteristics of the Sample (*N* = 142)

Demographic Characteristics	Frequency	Percent
Gender		
Male	71	50.0
Female	71	50.0
Marital Status		
Single, never married	61	43.3
Married	36	25.5
Widowed	18	12.8
Divorced	24	17.0
Living with partner	2	1.4
Educational Level		
Less than high school	30	21.6
High school graduate/GED	56	40.3
Some college/Technical school	30	21.6
Associate degree	12	8.6
Bachelor's degree	7	5.0
Advanced degree	4	2.9
Work Status		
Working full-time	23	16.5
Working part-time	5	3.6
Retired	39	28.1
Retired, volunteering	2	1.4
Disabled	44	31.7
Other	26	18.7
Heart Failure Stage		
Stage A	10	7.0
Stage B	15	10.6
Stage C	50	35.2
Stage D	67	47.2
Physical Activities Limited Because of Heart Failure		
Not limited	22	15.5
Somewhat limited	62	43.7
Limited	33	23.2
Very Limited	25	17.6

3.3 Instruments

Four instruments, original demographic survey (White, 2010), Heart Failure Self-Care Behavior Scale (HFSCBS; Artinian *et al.*, 2002), Spiritual Self-Care Practice Scale (SSCPS; White, 2010), and World Health Organization Quality of Life (WHOQOL BREF; World Health Organization, 1996). These instruments were selected because they were considered to measure aspects of the SCDNT, specifically, quality of life and self-care practices. The demographic survey, developed by the researcher, was used to obtain personal characteristics of the participants. In addition, the survey asked for information on Orem's basic conditioning factors, heart failure information, and spiritual/religious/traditional backgrounds, which was used in the larger study.

Heart Failure Self-Care Behavior Scale (HFSCBS; Artinian *et al.*, 2002). The HFSCBS was developed to measure the frequency with which HF patients performed 29 self-care behaviors. These behaviors are used to manage their chronic condition. The patients indicated the frequency of each behavior using a 6-point Likert-type scale ranging from 0 for *none of the time* to 5 for *all of the time*. Patients can complete the instrument in approximately 10 minutes. Responses on the 29 items are summed to obtain a total score ranging from 0 to 145, with higher scores indicating greater use of self-care behaviors to manage their HF. The HFSCBS was tested for content validity by having a panel of experts that included two nurse practitioners and two self-care experts review the scale. The instrument was tested for internal consistency using Cronbach alpha coefficients. The resultant alpha coefficient of .81 for the 29 items indicated the instrument as adequate internal consistency. Artinian *et al.* (2002), in another study, evaluated the internal consistency and obtained an alpha coefficient of .84, which was consistent with the earlier study.

To determine if the HFSCBS was reliable for the present study, Cronbach alpha coefficients were used to determine the internal consistency for the sample of African American patients diagnosed with HF. The resultant alpha coefficient of .86 was similar to that obtained in previous studies, indicating the instrument was reliable for the present study.

Readability. The results of the analysis using the Flesch-Kincaid readability index (Flesch, 1948) indicated that the HFSCBS had a reading level of 4.8. This finding indicated that people with an eighth grade reading level should be able to complete this scale with problems.

Spiritual Self-Care Practices Scale (SSCPS; White, 2010). The SSCPS is a 36-item questionnaire that measures the extent to which participants practice spiritual self-care actions. The 36 items were derived from a comprehensive review of literature on *spiritual practices*. The preliminary instrument was sent to four diverse religious leaders to evaluate the content validity of the items. The validators were asked to review the items and rate their relevance to spiritual practices using a 4-point scale ranging from 1 for *not a spiritual practice* to 4 for very *much a spiritual practice*. They also were asked to provide suggestions regarding the removal, addition, or rewording of items. The researcher reviewed the comments and responses on the surveys and made changes when a consensus was reached on removing an item or changing the wording to make it reflective of spiritual practices.

The participants were asked to rate the frequency with which they practiced each of the items on the SSCPS using a 5-point Likert scale ranging from 1 for never to 5 for always. The scores on each of the subscales were summed to obtain a total score. The total score for each subscale was divided by the number of items on the subscale to obtain a mean score. The use of mean scores provides outcomes that reflect the original unit of measurement and allows comparisons across the four subscales. The total score is calculated using the same procedure, with total scores ranging from 1 to 5.

Ratings on the SSCPS items from the 142 participants in the present study were used in a principal components factor analysis using a varimax rotation. Four factors emerged in the analysis: personal spiritual self-care practices, spiritual practices, physical spiritual practices, and interpersonal spiritual practices. The eigenvalues ranged from 2.77 to 6.00, indicating that each of the four factors was accounting for a statistically significant percent of variance.

To determine the reliability of the SSCPS, internal consistency coefficients were obtained using Cronbach alpha procedures (White, 2010). Results of these analyses indicated adequate to good internal consistency for each of the four subscales: personal spiritual self-care practices (.89), spiritual practices (.85), physical spiritual practices (.69), and interpersonal spiritual practices (.66). The alpha coefficient for the total scale was .91 indicating the scale had good internal consistency reliability.

Readability. The Flesch-Kincaid readability index (Flesch, 1948) for the SSCPS was at the 8th grade level. Of the 36 items, however, 34 items were at a 4th grade reading level. Two items, "Following a special diet (e.g., Kosher, Halal, vegetarian, etc.)" and "Wearing special clothing or jewelry (e.g., yarmulke, birka, cross, star of David)" included potentially unfamiliar polysyllabic words that increased the overall reading level substantially. However, these items were retained based on their importance in the overall purpose of the instrument.

World Health Organization - Quality of Life-BREF. The WHOQOL-100 is a valid, reliable measure of individual facets relating to QOL. The World Health Organization (WHO) developed the WHOQOL-BREF (1996) as a short form of the WHOQOL-100. The WHOQOL-BREF includes 26 questions, with one item from each of the 24 facets comprising the WHOQOL-100. The WHOQOL measures four dimensions of QOL: (a) physical health, (b) psychological, (c) social relationships, and (d) environment. For the purpose of this study, the total score on the WHOQOL will be used.

Miller *et al.,* (2008) reported on the validity of the WHOQOL-BREF. Construct validity of the WHOQOL-BREF was determined using exploratory and confirmatory factor analysis. The correlations between domains on the WHOQOL-BREF and the WHOQOL-100 (the parent instrument) ranged from .89 for social relationships to .95 for physical health. The WHOQOL-BREF also demonstrated good discriminative validity by being able to distinguish QOL between healthy and ill patients. Miller *et al.* (2008) reported on the reliability of the WHOQOL-BREF. Cronbach alpha coefficients ranged from .68 for social relationships to .82 for physical health. Yao and Wu (2005) tested the internal consistency with the obtained coefficients for a Taiwaniese sample ranging from .70 to .77 for the four domains. The range of test-retest reliability coefficients at 2-to 4-week intervals was from .41 to .79 at the individual item level and .76 to .80 for the four domains. Yao and Wu asserted that the WHOQOL-BREF had good psychometric properties for use with a Taiwanese population and could be used with other cultures.

Readability. The WHOQOL-BREF was tested for readability using the Flesch-Kincaid readability index (Flesch, 1948). The results of this analysis indicated the WHOQOL-BREF had a grade level of 5.2, indicating that individuals with a fifth grade reading level should be able to read and comprehend the items on the scale without a problem.

Data analysis. The data were analyzed using SPSS Ver. 20.0 to determine if spiritual self-care was mediating the relationship between heart failure self-care and quality of life. The four-step mediation analysis process (Baron and Kenney, 2012) was used in this analysis.

4 FINDINGS

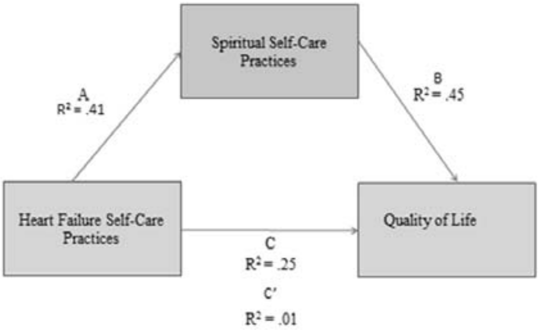
The mean score for heart failure self-care (*M*=3.63, *SD*=.75) was above the midpoint of the 5-point scale, indicating the participants' self-reported they were generally using many of the self-care practices for chronic illnesses. Spiritual self-care practices had a mean of 3.79 (*SD*= .59), providing support that the participants were using the self-care practices that were considered spiritual, but not necessarily religious. The WHO QOL mean score was 3.82 (*SD*=.70) on a 5-point scale, which indicated that participants had positive quality of life.

The first step of the mediation analysis used a linear regression analysis, with heart failure self-care practices as the independent variable, and quality of life as the dependent variable (See Table 2). A total of 25.2% ($p< .01$) of the variance in quality of life was accounted for by heart failure self-care practices. On the second step of the analysis, spiritual self-care practices was used as the dependent variable, and heart failure self-care practices was used as the independent variable. A statistically significant percentage of variance in spiritual self-care practices was explained by heart failure self-care practices (R^2=41.2%, $p< .01$). The results of the third step of the analysis indicated a statistically significant amount of variance in quality of life was explained by spiritual self-care practices (R^2=44.8%, $p< .01$). Because the criteria for the mediation analysis had been met on the first three steps, the fourth step was completed. Holding spiritual self-care practices constant, the relationship between heart failure self-care practices and quality of life was re-evaluated. The amount of variance explained by heart failure self-care practices decreased to 1.0% ($p= .136$), which was not statistically significant. Based on these findings, spiritual self-care practices was considered to be a statistically significant mediator of the relationship between heart failure self-care practices and quality of life. See Figure 2 for the mediation model.

Table 2. Mediation Analysis - Heart Failure Self-care Practices and Quality of Life with Spiritual Self-care Practices as the Mediator (*N* = 142)

Predictor	Outcomes	R^2	*F*	Standardized *β*
Step 1				
Heart Failure Self-care Practices	Quality of Life	.25	47.13	.50**
Step 2				
Heart Failure Self-care Practices	Spiritual Self-care Practices	.41	98.29	.64**
Step 3				
Spiritual Self-care Practices	Quality of Life	.45	113.81	.67**
Step 4				
Heart Failure Self-care Practices	Quality of Life	.18	30.30	.42**
Spiritual Self-care Practices	Quality of Life	.01	2.25	.12**
***p < .05; **p < .01**				

Figure 2. Mediation model - Relationship between heart failure self-care and quality



5 CONCLUSIONS

Heart failure is a chronic illness that can be managed when patients use appropriate self-care practices in conjunction with keeping doctor appointments and taking medications. Heart failure patients who use effective self-care practices can expect to have better outcomes for their chronic conditions. The use of spiritual self-care practices can enhance the relationship between heart failure self-care practices as a specific element within the SCDNT and quality of life. For many African Americans, spirituality is integrated through all aspects of their life, including health practices that influence their health beliefs and health outcomes that can then influence their self-care practices (Newlin *et al.*, 2002; Polzer and Miles, 2005).

Spiritual self-care is based on an individual's mind/spirit/body connection, upbringing, moral and religious background, and life experiences that originate from faith, feelings, and emotions. The use of spiritual self-care practices can promote quality of life through participation in interpersonal and intrapersonal activities that give meaning to life. Examples of spiritual self-care can include building social networks or volunteering (Liu *et al.*, 2008); listening to inspirational music (Stake-Nilsson *et al.*, 2009); meditation (Delaney, 2005); and developing a sense of inner peace and quiet (Kreitzer *et al.*, 2009). Other examples of spiritual self-care include practicing yoga or Tai Chi, attending religious services, reading sacred or inspirational texts, prayer or mediation, hiking, walking or otherwise enjoying nature, and developing or mending personal relationships. Whatever the spiritual self-care activity, the goal is the enhancement of spiritual well-being and overall health and well-being. White's theory of spirituality and spiritual self-care (WTSSSC) assesses for the use of spiritual self-care practices (White, 2010).

The function of mid-range theory is to develop a knowledge base that supports clinical decision making. This knowledge can provide a basis for predicting outcomes of nursing practice decisions (Blegen & Tripp-Reimer, 1997). To be practical across a wide array of nursing situations, a mid-range theory must be applicable in multiple settings, with patients who have differing health issues. Using Orem's (2001) SCDNT as a foundation, White (2010) developed the mid-range Theory of Spirituality and Spiritual Self-Care (WTSSSC). Once validated, this theory could be used in health promotion and disease mitigation to incorporate spirituality and spirituality self-care practices related to an individual's overall QOL. This study supported the importance of spiritual self-care as a mediator in the relationship between health deviation self-care as a part of Orem's SDCNT and quality of life. Additional research is needed to examine the role of White's midrange theory of spirituality and spiritual self-care practices (WTSSSC) that incorporates spiritual self-care as an enhancement to the health deviation component of Orem's SCDNT.

This study was limited to a sample of African Americans diagnosed with heart failure living in an urban area. The study needs to be extended to include a heterogeneous sample of people with diverse chronic illnesses who are living in urban, suburban, and rural areas. This further research can provide additional information regarding the reliability and validity of the SSCPS with diverse groups of people. Testing the relationship between spiritual self-care practices can further determine the importance of the addition of this construct to Orem's SCDNT.

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Congress Program

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Congress Program

WORLD CONGRESS ON FUTURE NURSING SYSTEMS
NEW APPROACHES - NEW EVIDENCE FOR 2020

12TH IOS WORLD CONGRESS
MAY 10–13, 2012
LUXEMBOURG

European Year for **Active Ageing**
and **Solidarity between Generations** *2012*

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Join your colleagues in contributing to the development of nursing science, particularly the science of self-care, at the 12th IOS World Congress to be held in Luxembourg May 10-13, 2012. Participants will explore the relationships among nursing sciences, self-care, dependent-care and nursing systems.

The scenic beauty of Luxembourg is well known all over Europe and abroad. The modern capital city is one of the biggest financial centers in the world and hosts a number of key European Union institutions and offices. The cultural wealth of the city has its origin in the geographical location at the crossroads of Latin and German cultures, as well as its past occupations by the Burgundians, the Spanish, the French, the Austrians and the Prussians. In 1994 the old town of Luxembourg and several historic buildings were recognized as UNESCO World Heritage. Thus, Luxembourg connects a thriving cultural life, rich history, excellent means of communication and an open spirit and is waiting to welcome you.

This World Congress will focus on the evidence of the effectiveness of nursing action in nursing systems that

- promote active aging
- facilitate dependent care and self-care to accomplish primary, secondary and tertiary goals.

Kathie Renpenning
President,
International
Orem Society for Nursing
Science and Scholarship

Mars
Di Bartolomeo
Minister of Social Security,
Minister of Health
Luxembourg

Conference Topics

- Active aging as a process to enhance quality of life and health
- Self-Care as human action and its development in various life situations
- Dependent-Care and its future demands
- Design of Nursing Systems and its impact on individuals, groups and the society at large
- Information and Communication Technologies (ICT) innovation in integrated care delivery systems
- Health Technology Assessment and its impact on self-care agency
- Nursing Ethics – Ethical interpretation of vulnerability, care and dignity
- SCDNT-based nursing education

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Thursday May 10, 2012

Congress Location
HÉMICYCLE CONFERENCE CENTER

All Keynote Presentations are subject to simultaneous translation.

14:00 H- 14:30 H	**Welcome Ceremony** M. Di Bartolomeo - Minister of Health, Minister of Social Security K. Renpenning - President of the International Orem Society
14:30 H- 15:15 H **Keynote 1**	**Prof. Dr. Susan Taylor, University of Columbia Missouri, USA** Moving forward – Demand for Nursing and Helping Systems in 2020 and beyond *Faire avancer - Les besoins en systèmes de soins jusqu'en 2020 et au-delà* *Vorausschauend agieren - Der Bedarf an Pflegesystemen bis 2020 und darüber hinaus*
15:15 H- 16:00 H **Keynote 2**	**Yuki Murakami, OECD, France** Seeking better value for money in Long-term care *Amélioration des résultats financiers pour les soins de longue durée* *Verbesserung des finanziellen Outcomes für die Langzeitpflege*
16:00 H- 16:30 H	**Coffee Break**
16:30 H- 17:15 H **Keynote 3**	**Prof. Dr. Chris Gastmans, Centre of Biomedical Ethics and Law, University of Leuven, Belgium** Dignity enhancing care for persons with dementia: An ethical interpretation of vulnerability, care and dignity *Le respect de la dignité en tant que principe dans la prise en charge des personnes atteintes de démence : une interprétation étique de la vulnérabilité, de l'accompagnement et de la dignité* *Die Beachtung der Würde als Grundlage der Betreuung von Menschen mit Demenz: Eine ethische Interpretation von Verletzlichkeit, Betreuung und Würde*
17:15 H- 18:00 H **Keynote 4**	**Prof. Dr. Tiny Jaarsma, University of Linköping, Sweden** Using the concept Self-Care in patients care: New challenges or old news? *L'utilisation de concepts d'auto-soins dans le traitement et le suivi des patients : nouveaux challenges ou anciennes innovations ?* *Die Nutzung der Konzepte der Selbstpflege in der Patientenversorgung und -betreuung: Neue Herausforderungen oder alte Neuigkeiten?*
18:30 H **Special Program**	**Cocktail Reception** Bar de Hemicycle *Tickets available at the Congress Office. Please register in advance.*

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Friday May 11, 2012 **Congress Location**
ABBAYE DE NEUMÜNSTER

	CONCURRENT SESSSION A **Room A22-J.Ensch** *Presentation Languages* 🇬🇧 🇫🇷 *Simultaneous Translation*	**CONCURRENT SESSSION B** **Room A21-E. Dune** *Presentation Languages* 🇬🇧 🇩🇪 *Simultaneous Translation*	**CONCURRENT SESSSION C** **Room Espace Nic Klecker** *Presentation Language* 🇬🇧
Topics	***Active Ageing***	***Self-Care as Human Action***	***Nursing Systems***
09:00 H	A1: „Preventive home visits“ to people aged 80 and over in Tyrol/Austria – A cross-sectional study Visites à domicile préventives pour les personnes âgées au Tyrol - Résultats d‘une étude représentative *Ch. Them*	B1: Spiritual Self-Care as an Extension of Orem's Self-Care Deficit Nursing Theory Spirituelle Aspekte der Pflege: eine Erweiterung von Orems Pflegekonzepten *M. White*	C1: Use of Orem‘s Self-Care Deficit Nursing Theory in the Self-Management Education of patients with TYPE 2 diabetes: A Case Study *H. Arda Sürücü*
09:25 H	A2: Cooperative Work of welfare mix in helping systems for eldely and families Travail de coopération sur une approche multidisciplinaire pour les personnes âgées et les aidants naturels *M. Opielka*	B2: The nutrition self care inventory Das Selbstpflegeeinschätzungsinstrument bei Ernährung *L.M. Fleck*	C2: The prescribing practices of nurses who care for patients with skin conditions in the UK : a questionnaire survey *N. Carey*
09:50 H	A3: Validity and internal consistency of mobility scales for healthy older people in Germany Validité et cohérence de l‘échelle de mobilité dans une application auprès de personnes âgées en bonne santé en Allemagne *A. Brühl*	B3: Facing the bittersweet symphony of diabetes: contribution of the self-regulation theories in adjustment to type 1 diabetes Der Umgang mit der bittersüßen Seite des Diabetes: Der Beitrag der Selbstregulationstheorien bei der Einstellung des Typ 1 Diabetes *S. Recchia*	C3: Development of Self–Care Handbook in Preventing Stroke for Persons with Hypertension *N. Thepwan*
10:15 H	A4: Better QOL for the elderly by Kinaesthetics employed in nursing practice Influence de la proprioception appliquée dans la pratique des soins sur la qualité de vie des personnes âgées *H. Tadaura*	B4: Client focused counseling and support based on self-care requisites defined by Orem in a context of salutogenesis Von der Pathogenese zur Salutogenese - Klientenzentrierte Beratung und Begleitung auf der Basis der Selbstpflegeerfordernisse von Dorothea Orem *I. Bürk*	
10:35 H	**Coffee Break**		

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Friday May 11, 2012 **Congress Location**
ABBAYE DE NEUMÜNSTER

	CONCURRENT SESSSION D **Room A22-J.Ensch** *Presentation Languages* 🇬🇧 🇫🇷 *Simultaneous Translation*	**CONCURRENT SESSSION E** **Room A21-E. Dune** *Presentation Languages* 🇬🇧 🇩🇪 *Simultaneous Translation*	**CONCURRENT SESSSION F** **Room Espace Nic Klecker** *Presentation Language* 🇬🇧
Topics	***Self-Care as Human Action***	***Information Communication Technology (ICT)***	***Nursing Ethics***
11:15 H	D1: Capability for Dietary Control among Muslim Thais Risky to Diabetes Capacité de contrôle de l'alimentation chez les citoyens thaïlandais musulmans présentant un risque de diabète *C. Insuwan*	E1: Bridging gaps in ICT and ageing: Designing high-tech solutions for the tech-“no“-generation Lückenschluss zwischen IKT und Altern: Entwicklung von Hightech-Lösungen für die technikunerfahrene Generation *M. Hoffmann*	F1: Orem's Self-Care Deficit Nursing Theory as a Foundation for the Care of Adolescent Mothers *V. Burns*
11:40 H	D2: Therapeutic self-care demand of people with COLD – Clinical Pathway and interdisciplinary systematic education Besoins en soins chez les patients atteints de BPCO - Parcours clinique et enseignement pluridisciplinaire des patients *I. Flüs*	E2: Domiphone, an innovative tool for a better quality and control of home care services Domiphone: Ein innovatives Instrument für eine bessere Lebensqualität und dem Umgang mit häuslichen Versorgungsleistungen *N. Renaudin*	F2: Who decides at the end of life? Decision-making processes related to administration of artificial nutrition and hydration in patients with dementia. Nurses' role. *M. Haas*
12:00 H	**Lunch Break**		

	CONCURRENT SESSSION D **Room A22-J.Ensch**	**CONCURRENT SESSSION E** **Room A21-E. Dune**	**CONCURRENT SESSSION F** **Room Espace Nic Klecker**
Topics	***Information Communication Technology (ICT)***	***Nursing Systems***	***Self & Dependent Care***
14:00 H	D3: New technologies of care during pregnancy and for the support of parents Les nouvelles technologies dans la prise en charge soignante de la grossesse et la parentalité *B. Atanasova*	E3: Case-oriented nursing system at Friedrich-Ebert-Hospital Newmuenster - Reflecting a 10 year process of development. Fallorientierte Pflegeorganisation am Friedrich-Ebert-Krankenhaus Neumünster (FEK) - 10 Jahre klinische, theoriebasierte Fallsteuerung *Ch. Thielecke*	F3: Relationship between self-care agency, self-care practices and obesity among rural midlife women *L. Burdette*
14:25 H	D4: Integration of electronic patient records at Stëftung Hëllef Doheem Projet du dossier de soins électronique à la «Stëftung Hëllef Doheem» *A. Koch*	E4: SCDNT as foundational structure for the development of an operational design for a nursing facility Die Selbstpflegedefizit-Theorie (SPDT) als Grundlage des Betreiberkonzeptes in einer Altenpflegeeinrichtung *Ch. Zwinscher*	F4: Development of Handbook of Chronic Foot Ulcer Prevention for Farmers With Diabetes *A. Punritdum*

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Friday May 11, 2012 **Congress Location**
ABBAYE DE NEUMÜNSTER

Topics	**CONCURRENT SESSSION G** **Room A22-J.Ensch** *Presentation Languages* 🇬🇧 🇫🇷 *Simultaneous Translation* ***Nursing Systems***	**CONCURRENT SESSSION H** **Room A21-E. Dune** *Presentation Languages* 🇬🇧 🇩🇪 *Simultaneous Translation* ***Self-Care as Human Action***	**CONCURRENT SESSSION I** **Room Espace Nic Klecker** *Presentation Language* 🇬🇧 ***Self & Dependent Care***
15:00 H	G1: Prescribing for pain - what do nurses contribute? A UK questionnaire survey Prescription médicale de thérapies contre la douleur. Quels rôles joient les soignants? Une étude menée en Grande-Bretagne *K. Stenner*	H1: Development of self-care agency through enhancement of motivation in people with schizophrenia Die Entwicklung von Selbstpflegekompetenz durch Motivationssteigerung bei Menschen mit einer Schizophrenie *J. Pickens*	I1: The Caregives' Utilization of Child Care Handbook and Their Care Actions on Promoting Cognitive Development for Thai Children Aged 2-5 Years *P. Nujinda*
15:25 H	G2: Development of Continuing Care Options for Patients with Tuberculosis Développement de possibilités de soins durables chez les patients atteints de tuberculose *S. Detthippornpong*	H2: Prevalence of measures involving deprivation of liberty within nursing homes: Evaluation and interventions of reduction Zur Prävalenz freiheitsentziehender Maßnahmen (FEM) in der Altenpflege: Bestandsaufnahme, Möglichkeiten und Grenzen der Reduzierung *W. Billen*	I2: Self-care practices of Thai nursing students *M. Arpanantikul*
15:50 H	G3: Developing and Testing an Exercise Promoting Program of Community Health Leaders in Thailand Développement et test d'un programme d'activités physiques chez les cadres thaïlandais dans le secteur de la santé *C. Ekkarat*	H3: Constructs of becoming a dependent care agent - An analysis for the viewpoint of care taker and care recipient Konstrukte zur Pflegeübernahme – eine Analyse aus der Perspektive von pflegenden Angehörigen und Pflegebedürftigen *K. Rädel*	I3: An overview of non-medical prescribing across one UK strategic health authority: a questionnaire survey *N. Carey*
16:15 H		H4: The difference between patient consulting and information Informieren Sie noch – oder beraten Sie schon? Beratung in der Pflege – (k)eine Frage der Haltung und Kompetenzen *I. Bürk*	I4: An Analysis of Self-Care Knowledge of Hepatitis B Patients *Th. Luu*
16:35 H	**End of Program**		
17:30 H	**IOS Business Meeting**	**Room A22-J.Ensch**	

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Saturday May 12, 2012 **Congress Location**
ABBAYE DE NEUMÜNSTER

	CONCURRENT SESSSION J **Room A22-J.Ensch** *Presentation Languages* 🇬🇧 🇫🇷 *Simultaneous Translation*	**CONCURRENT SESSSION K** **Room A21-E. Dune** *Presentation Languages* 🇬🇧 🇩🇪 *Simultaneous Translation*	**CONCURRENT SESSSION L** **Room Espace Nic Klecker** *Presentation Language* 🇬🇧
Topics	***Dependent Care***	***Nursing Education***	***Active Ageing***
09:00 H	J1: The development of functional stability and self-care cababilities of elderly during intensive care treatment Evolution fonctionnelle et capacités d'auto-soins des patients âgés hospitalisés en soins aigus *A. D'Onofrio*	K1: 2012 Update on the Self-Care Deficit Nursing Theory as a curriculum conceptual framework in baccalaureate education Die Selbstpflegedefizit-Theorie als curriculare Grundlage eines Bachelorprogramms - Ein Neubewertung in 2012 *V. Berbiglia*	L1: Residential care for older persons in Belgium: what are the future needs? Projections of residential care users 2010 – 2025 *K. Van den Bosch*
09:25 H	J2: Bedriddenness in long-term care - prevalence and influencing factors Besoins en soutien pour les soins aux personnes dépendantes compte tenu des attentes individuelles envers les aidants professionnels *S. Schrank*	K2: A self-care deficit approach to integrating technology into online and traditional classrooms. Der Selbstpflegedefizit-Ansatz zur Integration neuerer Technologien in virtuellen und traditionellen Klassenräumen *L.M. Stover*	L2: Theory based development of indicators as the foundation of an active design of demographic change in rural areas. *M. Heuberger*
09:50 H	J3: The study of self-care agency based on Orem's theory in individuals with hypertension admitted in the selected hospitals of Ardebil (Iran). La compétence en auto-soins chez les personnes atteintes d'hypertension artérielle admises dans des cliniques sélectionnées à Ardebil (Iran) *F.B. Farahani*	K3: Challenging RN-BSN students to apply Orem's theory to practice. Möglichkeiten um Bachelorstudierende für die Nutzung der Selbstpflegedefizit-Theorie in der Praxis zu befähigen *S. Davidson*	L3: Exploring Facilitators and Barriers to Healthy Ageing *H. Taggart*
10:15 H	J4: SCNDT: A foundation for practice, education and research La théorie de déficit d'auto-soin en tant que base pour la pratique, la formation et la recherche *K. Renpenning*	K4: Development of a curriculum for nursing education based on SCDNT (Self-Care Deficit Nursing Theory) Entwicklung eines Curriculums für die Pflegeausbildung auf Grundlage der SPDT *S. Watzke*	
10:35 H	**Coffee Break**		

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Saturday May 12, 2012 **Congress Location**
ABBAYE DE NEUMÜNSTER

	WORKSHOP 1 **Room A22-J.Ensch** *Presentation Languages* 🇬🇧 🇫🇷 *Simultaneous Translation*	**WORKSHOP 2** **Room A21-E. Dune** *Presentation Languages* 🇬🇧 🇩🇪 *Simultaneous Translation*	**WORKSHOP 3** **Room Espace Nic Klecker** *Presentation Language* 🇬🇧
Topics	**People in motion - Creating perspectives Part 1** *H. Bauder Mißbach*	**Economics meets Nursing Systems** *O. Scupin*	**Nursing Design** *K. Renpenning* *S.G. Taylor*
11:15 H	Kinesthetic in practical nursing settings and nursing therapeutic interventions. Encouragement de mouvement pendant le soin quotidien et dans des interventions thérapeutiques de soin	Development of a sector-wide cost unit accounting system as a steering and planning instrument for institutional long-term care in Luxembourg Entwicklung einer sektorweiten Kostenträgerrechnung als Steuerungs- und Planungsinstrument für stationäre Altenpflege in Luxemburg.	Design the core professional process and SCDNT
12:00 H	**Lunch Break**		

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PROGRAM UPDATE May 12, 2012

Saturday May 12, 2012

12:45 H **-** **13.45 H**	VISITING Hospice Civil Pfaffenthal Rue Mohrfels 71 2158 Luxembourg		ADDITIONAL OPTION
	We offer a tour to this outstanding nursing institution which is well known for its nursing service in Luxembourg. Currently it is a model project for the care of dementia patients.	**Please note!** You need to sign up at the registration desk. Please indicate your choice of language at registration. 🇬🇧 🇩🇪	Transportation 10 minutes scenic walk or use our shuttle service. Meet us 12:30 H at the registration desk.

14:00 H POSTER SESSION (Salle Agora Macel Jullian)

Additional information on Workshop 4, 5, 6 and 7
Your are requested to sign up for a workshop at the registration desk. Please indicate your choice of language for the workshop you want to join.

14:00 H **-** **16.10 H**	WORKSHOP 4 People in motion - Creating perspectives Part 2 H. Bauder Mißbach	WORKSHOP 4 LOCATION Hospice Civil Pfaffenthal Room Kinaesthetic	
	In this workshop you'll have the oportunity to work with a team of experts in using kinesthetic methods for nursing practice situations.	This workshop will be held in three languages. 🇬🇧 🇫🇷 🇩🇪	Transportation 10 minutes scenic walk or use our shuttle service. Meet us 13:45 H at the registration desk.

	WORKSHOP 5 Room A22-J.Ensch Presentation Languages 🇬🇧 🇫🇷 Simultaneous Translation	**WORKSHOP 7** **Room A21-E. Dune** **Presentation Languages** 🇬🇧 🇩🇪 **Simultaneous Translation**	WORKSHOP 6 Room Espace Nic Klecker Presentation Language 🇬🇧
Topics	Health Technology Assessment (HTA) in Nursing H.-P. Dauben, C.-B. Pierl	**Perspectives in Active Ageing from Finland** **L. Karjaluoto**	Self-care Deficit Nursing Theory (SCDNT) Curriculum S. Metcalfe, V. Folse
15:00 H	Presentation of HTA strategies and methods in three parts. Vorstellung verschiedener HTA Strategien für die Pflege.	Presentation of strategies to reduce healthcare costs through exercise for the elderly based on technical and architectual concepts. Case Studies from Switzerland E. van het Reve	Part I: Balancing demands and overcoming barriers to successful implementation Part II: Curricular revision and design Part III: Teaching strategies

16:10 H **End of Program**

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Saturday May 12, 2012

19:00 H

GALA DINNER
Location
ABBAYE DE NEUMÜNSTER
Salle Agora Marcel Jullian
Gourmet Menue and Music
Presentation of the AWARD WINNERS

Sunday May 13, 2012

Congress Location
ABBAYE DE NEUMÜNSTER (Salle Robert Krieps)

All Keynote Presentations are subject to simultaneous translation.

09:00 H- 09:45 H **Keynote 5**	**Prof. Dr. Somchit Harnucharurnkul, Department of Nursing, Faculty of Medicine, Mahidol University Bangkok, Thailand** Self-care in the context of nursing and health care system in Thailand *L'auto-soin dans le contexte des systèmes de soins et de santé en Thaïlande* *Selbstpflege im Kontext der Pflege- und Gesundheitssysteme in Thailand*
09:45 H- 10:30 H **Keynote 6**	**Prof. Dr. Beth Geden, Family Health Center, Columbia, Missouri, USA** One size doesn't fit all: Negotiating self-care demands *Une solution adaptée à chaque situation : négocier les besoins en auto-soin* *Eine Lösung passt nicht für alle Situationen: Selbstpflegebedarfe verhandeln*
10:30 H- 11:00 H	**Coffee Break**
11:00 H- 11:45 H **Keynote 7**	**Rodd Bond, Netwell Centre, Dundalk Institute of Technology, Ireland** Redefining Information Communicaton Technology (ICT) - Integrated Care Transformation *Rédefinition des technologies de l'information et de la communication (TIC) - Transformation des soins intégrés* *Neudefinition von Informations- und Kommunikationstechnologie (IKT) - Wandel der Integrierten Versorgung*
11:45 H- 12:45 H **Keynote 8**	**Marianne Van den Berg, European Commission, Unit Innovation for Health and Consumers, Brussels, Belgium** The European Innovation Partnership on Active and Healthy Ageing Les initiatives des partenaires européens pour un vieillissement actif et en bonne santé *Die europäische Partnerinitiativen für aktives und gesundes Altern* **Niclas Jacobson, Ministry of Health and Social Affairs, Stockholm, Sweden** Europe 2020: What strategy for active ageing? *Europe 2020 - Quelles stratégies pour un vieillissement actif ?* *Europa 2020: Welche Strategien für das aktive Altern?*
12:45 H	**CLOSING CEREMONY**
13:15 H	**End of the Conference Program**

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Poster Session (Salle Agora Michel Jullian)

Saturday May 12, 2012
14:00 H - 15:00 H

Active aging and self-care among the elderly within the social-economic context of Armenia	H. Shaboyan
Attitude of the elderly face the dependence on self-care for walk, after surgery for fracture of the proximal femur	P. Câmara
Auswirkungen von Belastungen aus der Dependenzpflege auf die Selbstpflegesysteme pflegender Angehöriger	M. Knie
Bedingungen zum Aufbau erfolgreicher Dependenzpflegesysteme - Ein länderübergreifender Vergleich dargestellt an zwei Fallstudien	E. Vojtková
Characteristics in diabetes self-care agency by Statistical Cluster Analysis	Y. Shimizu
Connecting nursing theory with practice through education based on Self-Care Deficit Nursing Theory and utilization of nursing record	H. Tadaura
Ermitteln des Situativen Selbstpflegebedarfs von Patienten mit einer Nichtinvasiven Ventilation (NIV) bei COPD	S. Geisenfelder
Workplace Wellness Program for Nurses: A Logic Model Approach	E. A. Iellamo
Notaufnahme und Pflegediagnostik	M. Hohdorf
Nursing Process: Utilization of Dorothea's Orem theory in an Adult Clinical	H. Fernandez
Self care approach from a physical side for people with schizophrenia--To promote the self care agency of people with schizophrenia	Y. Endo
Strukturierte Schulungsgespräche im klinischen Kontext - am Beispiel der Situativen Problematik „veränderte Atmung von Patienten mit COPD"	H. Schell
Verlaufsformen von Dependenzpflegesystemen dargestellt am Übergang zum professionellen Pflegesystem - Eine Fallstudie	A. Strugmann
Unterstützungsbedarfe für Dependenzpflegende unter Berücksichtigung individueller Erwartungen an professionelle Pflegende	St. Auer
Using the theory of self-care deficit to identify unmet supportive care needs of lung cancer patients during the chemotherapy phase: descriptive design	A. Serena

Keynote Speaker and Presenter

Arda Sürücü, Hamdiye, Dokuz Eylul University Faculty of Nursing, TR, Izmir
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Berbiglia, Dr. Violeta, Berbiglia Educational Consultants, US, Helotes, Tx
Billen, Wolfgang, University of Luxemborg, LU, Wasserbillig
Bond, Rodd, Netwell Centre, Dundalk Institute of Technology, IRE, Dundalk
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Câmara, Patrícia, PT, Funchal
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Ekkarat, Chuleeporn, Nursing Faculty, TH, Songkhla
Endo, Dr. Yoshimi, JP, Suita
Farahani, Prof. Dr. Behnaz, Islamic Azad University of Iran UAE Branch, AE, Dubai
Fernandez, Prof. Dr. Higinio, University of Veracruz, MX, Papantla
Fleck, Dr. Laureen, Florida Atlantic University, US, Boca Raton
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Gastmans, Prof. Dr. Chris, University Leuven, BE, Leuven
Geden, Prof. Dr. Beth, Family Health Center, US, Columbia, MO
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Harnucharukul, Prof. Dr. Somchit, Mahidol University Faculty of Nursing, TH, Bangkok
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Hoffmann, Martine, RBS Center fir Altersfroen, LU, Itzig
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Insuwan, Chalermsri, Nursing Faculty, TH, Songkhla
Jaarsma, Prof. Dr. Tiny, University of Linköping, SE, Linköping
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Knie, Marita, Klinikum Kempten, DE, Oy-Mittelberg
Koch, Alain, Stëftung Hëllef Doheem, LU, Luxembourg

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Murakami, Yuki, OECD Directorate for Employment, Labour and Social Affairs, FR, Paris
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Serena, Andrea, U of Applied Science Western Switzerland, CH, Fribourg
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Shimizu, Prof. Dr. Yasuko, Osaka University, JP, Osaka
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Strugmann, Anke, Z&L Pflege GmbH, DE, Lichtenau
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Taylor, Prof. Dr. Susan, Sinclair School of Nursing, US, Columbia, MO
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Vojtkova, Eva, ZL Pflege GmbH, DE, Chemnitz
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Objectives

Upon completion of the conference, participants will be able to:

1. Articulate the relationship between nursing sciences and the science of self-care.
2. Contribute to the continuing development of self-care deficit nursing theory and the science of self-care.
3. Utilize knowledge from the nursing sciences in developing systems of living for active aging.
4. Contribute to the development and utilization of nursing sciences in the design of systems for enrichment of dependent-care.
5. Design nursing science-based programs to measure nursing effectiveness.
6. Utilize theories of self-care to facilitate critical analysis and revision of nursing systems.
7. Develop particularized practice models that recognize basic conditioning factors such as age, chronic illness, family and sociocultural/political systems that impact achieving goals related to active living and active aging.
8. Foster self-care deficit nursing theory-based education in a variety of settings.
9. Describe the processes needed for students to develop an evidence-based nursing perspective.
10. Design curricula which reflect the integration of nursing cases and nursing science.

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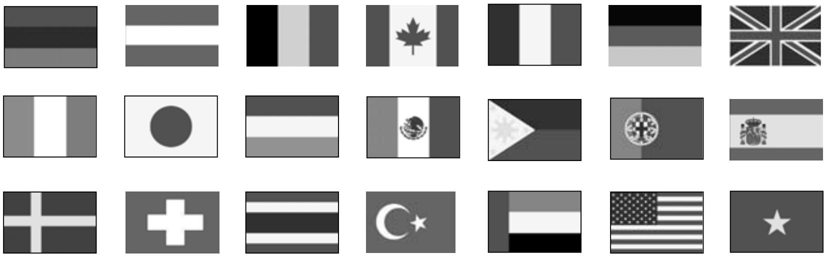

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