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The Effect of Overactive Bladder Syndrome on Health-Related Quality of Life in an Assisted-Living Community

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The Effect of Overactive Bladder Syndrome on Health-Related Quality of Life in an Assisted-Living Community

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B.A. The Johns Hopkins University, 2007

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APPROVAL PAGE

Master of Public Health Thesis

The Effect of Overactive Bladder Syndrome on Health-Related Quality of Life in an Assisted-Living Community

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TABLE CONTENTS

	<u>Page</u>
Approval Page	ii
Acknowledgements	iii
List of Tables	vi
Abstract	vii
Introduction	1
Literature Review	2
Assisted-living communities	2
Factors influencing quality of life in assisted-living residences	3
Health-related quality of life	5
HRQOL assessment tools and the SF-20	5
Overactive bladder syndrome	6
Background and significance of OAB	7
The Study	10
Purpose	10
Hypotheses	11
Methods	11
<i>Setting</i>	11
<i>Subjects</i>	12
<i>Variables</i>	13
<i>Data analysis</i>	16
Scale construction for the SF-20	16
Scoring the OABSS	18
Statistical analyses	18
Results	18
<i>HRQOL scores</i>	19

<i>OABSS scores</i>	19
<i>Regression</i>	20
Discussion	20
Limitations	22
Conclusions and significance in the field of public health	23
Appendix A – Study flyer	25
Appendix B – Informed Consent Form	26
Appendix C	29
Health-Related Quality of Life Questionnaire	29
Overactive Bladder Symptom Score (OABSS)	31
References	32

LIST OF TABLES

	<u>Page</u>
Table 1. Definitions of Health Concept in SF-20	14
Table 2. Transforming item scores linearly to common metric with range of 0-100	17
Table 3. Mean HRQOL composite score and subscores	19
Table 4. Pearson's r and p -values for age, HRQOL, and each of the HRQOL measures as a function of OABSS	20

ABSTRACT

This study investigated the effect of overactive bladder syndrome on the health-related quality of life of 32 residents (mean age 85.4) living in an assisted-living community, using widely-used and well-validated questionnaires (the OABSS and the SF-20, to assess overactive bladder and health-related quality of life, respectively). Approximately 31% of the study population satisfied the criteria for the diagnosis of overactive bladder syndrome. No significant correlation was found between the subjects' scores on the overactive bladder and health related quality of life inventories. Nor was any association found between overactive bladder symptoms and the six component measures of the SF-20 (physical functioning, role functioning, social functioning, mental health, health perceptions, and pain). These results are consistent with the notion that living in an assisted-living community may maintain social support, autonomy, and independence in the face of real or anticipated physical decline, thus the negative effect of chronic health conditions on life-satisfaction. Such communities may thus promote gerotranscendence, the ability to redefine oneself based on a rational approach to physical and mental strengths and weaknesses, while diminishing preoccupation with health status.

Introduction

The American population is aging. Largely due to an increase in life expectancy and advances in the diagnosis and treatment of acute and chronic illness, the number of adults over 65 is expected to approach 72 million by the year 2030, with senior adults comprising fully 20% of the U. S. population (Vincent & Velkoff, 2010). A concomitant of this enhanced longevity has been an upsurge in the number of Americans living with multifactorial disabilities, in large part as a function of age. In fact, it has been estimated that the disability rate of seniors over 75 is eight times that of individuals less than 45 (Wedgewood, 1985), and that by 2050, almost 27 million senior adults will need some level of assistance in dealing with their health conditions and in performing the necessary activities of daily living (ADLs) (Kozar-Westman, Troutman-Jordan, & Nies, 2013).

These statistics, however, have had some positive consequences. Over the past few decades, they have impelled public health agencies and private and municipal community planners to focus on ways for seniors to *age in place* (Wiles et al., 2012), either by encouraging modifications to existing homes, or designing and constructing residences that allow for a significant degree of retained privacy and autonomy (Ball et al., 2000). Among such housing arrangements is the assisted-living community (ALC). While the definition of this entity has evolved since its first use, ALCs are, in essence, community-based, residential environments that offer housing, meal services, and assistance with medications and the performance of ADLs and instrumental ADLs (IADLs) in a graded fashion, depending on the needs of the resident (Kane, Chan, & Kane, 2007; Doron and Lightman, 2003).

Quality of life (QOL) has become an increasingly important consideration in planning such housing environments for seniors, especially those with physical limitations, and in evaluating the outcomes of planned communities (Mitchell & Kemp, 2000; Ferrans, 1996). QOL is a multidimensional construct that depends on such determinants as social involvement,

physical functioning, and health (Raphael, 1996; Lawton, 1991). With regard to the latter factor, declining mental and physical health can have a markedly deleterious effect on the ability of elderly populations to adjust to age-segregated living situations (Mitchell & Kemp, 2000). To date, only a few studies have examined the effect of particular health conditions on health-related quality of life (HRQOL). Such investigations have focused on non-specific adult populations rather than senior adults living in retirement communities (Lieberman et al., 2001).

The aim of this study is to assess the prevalence of a specific health issue, the overactive bladder syndrome (OAB), a syndrome characterized by urinary urgency, frequency, nocturia (the need to awaken at night to urinate), and often incontinence, in a sample of the female residents of an assisted living facility in the greater Hartford, Connecticut region, and to determine the effect of this symptom complex on the HRQOL of these individuals. Since adjustment to life in age-segregated communities can be difficult for elderly individuals with physical infirmities (Hu et al., 2003), it is important to recognize health conditions in this segment of the population in order to maximize independence, social interaction, and quality of life in the assisted living population.

Literature Review

Assisted-living communities

As noted, the definition of an assisted-living community is a broad one that applies to a wide range of residential settings for older adults. In 2003, however, the U. S. Senate Special Committee on Aging provided a definition to Congress that described ALCs as a communities that “provide or coordinate oversight and services to meet individualized scheduled needs, based on assessments and service plans, and unscheduled needs” (Assisted Living Workgroup, 2003). Among the services specifically cited were a 24-hour awake staff, provision of personal, supportive, and health-related services, recreational activities, meals, housekeeping, laundry, and

transportation (Assisted Living Workgroup, 2003). In its modern iteration, therefore, an ALC provides a non-institutional living setting where seniors can retain significant independence, privacy, and control of their daily activities in a setting where needs that exceed the provision of meals and housekeeping can be met (Zimmerman & Sloane, 2007).

Some assisted-living communities are part of a continuing care retirement community (CCRC), a progressive living situation in which older adults, almost exclusively of higher socioeconomic status, enter the neighborhood functioning independently, with the opportunity to avail themselves of gradually increasing support services, as their health status and ability to perform standard ADLs declines (Aylan & Greed, 2015). Most CCRCs have nursing homes on the property for those residents whose physical and mental conditions have deteriorated to the point of requiring skilled nursing (Hayes et al., 2001). Of note, there has been a developing trend for residents of CCRCs to enter the assisted-living community with more significant limitations in their ability to perform ADLs. For example, an analysis of data from the National Medicare Beneficiaries Survey (Spillman, Liu, & McGilliard, 2002) revealed that the number of assisted-living residents requiring aid with the execution of three or more ADLs increased from 35% in 1992 to more than 50% in 1998, suggesting, perhaps, a reluctance of these senior adults to go directly to a nursing home facility and a greater willingness of the ALC to accept them.

Factors influencing quality of life in assisted-living residences

The decision to move to an assisted-living community is considered by many seniors to be a major life decision and one of the most stressful events in their lives (Stokes & Gordon, 1988). The transition is often quite disruptive, especially when it is precipitated by the progression of illness or the loss of a spouse (Hawes, Rose, & Phillips, 1999). However, when the decision to move is voluntary, the level of anxiety is generally diminished (Stavely, 1997).

The dynamic of adjustment to an ALC depends on variables in a wide range of different domains, including: the reasons for making the transition to the ALC, distance from family and friends, concerns about autonomy and control, the physical environment of the facility, participation in social activities, and the mental and physical health of the individual (Mitchell & Kemp, 2000). Negative adjustment to the new residential milieu is compounded by decreased health status, decreased ability to accomplish ADLs, diminished cognitive capacity, social isolation, and long-standing depression (Rossen, 2007; Cummings, 2002).

Improved quality of life has been the goal of the *aging in place* philosophy, with greater independence and autonomy ranking highest among the most important QOL components cited by senior adults (Chapin & Dobbs-Kepper, 2001; Ball et al., 2000; Mitchell & Kemp, 2000; Yee et al., 1999). These characteristics, along with privacy, are similarly mentioned by those living in ALCs (Street et al., 2007; Williams, 1991). Lawton (1991), focusing on quality of life issues specifically related to the elderly, centered his definition of QOL on social involvement, psychological well-being, environmental factors, and health. Although significant variance in estimates of quality of life has been reported, due to differences in the objective and subjective indicators used, studies have uniformly found a compelling correlation between health status and QOL ratings (Rossen, 2007; Cummings, 2002; Kingston et al., 2001; Mitchell & Kemp, 2000; Gould, 1992; Osberg et al., 1987). In fact, the relationship between perceived QOL and the mental and physical health of adult seniors appears to be reciprocal. Decreased life satisfaction adversely impacts objective indices of these parameters (Gutheil, 1991; Compton, 1989).

Health-related quality of life

The frequently diminished health status of senior adults, coupled with the fear of future dependency, social isolation, and loneliness, has made the assessment of health-related quality of life (HRQOL) of special interest to health providers, policymakers, and those involved in planning assisted living communities (Byam-Williams & Salyer, 2010; Rossen, 2007; Kingston et al., 2001; Mitchell & Kemp, 2000; Ferrans, 1996). Having the ability to measure HRQOL using well-validated, reliable and reproducible instruments is helpful when assessing the psychological impact of chronic disease in the elderly, both cross-sectionally and longitudinally over time (Kingston et al., 2001; Guyatt, Feeny, & Patrick, 1993). Indices of HRQOL are also valuable in determining the efficacy of programs aimed at improving the life satisfaction of seniors burdened with disabilities and in formulating the appropriate patterns of expenditure to maximize the success of such initiatives (Guyatt et al., 1995). In addition, from a social science and public health standpoint, measuring HRQOL can potentially help explain why different individuals with the same types of premorbid conditions respond differently to challenges that threaten their ability to live satisfying lives into old age (Guyatt et al., 1995).

HRQOL assessment tools and the SF-20

The value of measuring HRQOL in the elderly population is clear. However, developing a reliable and valid instrument for this purpose has had to balance these requirements with the practicality of creating an index that would not require an onerously long time for a subject to complete. Some of the early questionnaires designed for this purpose took 30 to 45 minutes to finish, a far longer time than many study participants were willing to devote (Stewart, Hays, & Ware, 1988). This observation resulted in surveys based on only a few single-item questions (Spitzer et al., 1981). Such simple measures, while easy to fill out, were plagued by inferior

reliability and validity (Stewart, Hays, & Ware, 1988). In recognition of the deficiencies of extremely short inventories, as well as the long completion time necessary to complete long questionnaires, the MOS 20-item Short-Form Health Survey (SF-20) was created, using measures culled from several longer questionnaires (Ware et al., 1988). Since that time, this twenty-item instrument has been extensively reviewed, and has met reliability and validity standards (Carver et al., 1999; McHorney et al., 1992; Stewart, Hays, & Ware, 1988).

Overactive bladder syndrome

Overactive bladder syndrome (OAB) is a clinically diagnosed syndrome characterized by urinary urgency, frequency (> 8 micturitions per day), and nocturia. It is frequently associated with urge incontinence (involuntary emptying of the bladder) (Haylen et al., 2010; Homma et al., 2006; Abrams et al., 2003). The cardinal symptom is a strong, unpredictable, and sudden need to urinate which is difficult to defer (Hu et al., 2003). Since voiding cannot be postponed, this urgency leads to an increased frequency of micturition (i.e., a decreased intervoid interval) (Chappel et al., 2005). Although urgency is the hallmark of OAB, a strict definition of this syndrome has gone wanting in studies of this disorder, particularly in assessments of the efficacy of the wide array of treatments used to ameliorate symptoms. Nevertheless, there is consensus that a diagnosis of OAB requires the presence of urinary urgency and frequency, occurring both day and night (Stewart et al., 2003). Up to 60% of individuals with OAB do not have urge incontinence, however. An additional prerequisite for the diagnosis of OAB is the exclusion of a urinary tract infection, the absence of a neurogenic etiology for the symptoms, and the ruling out of other potentially causal disorders, such as polydipsia (excessive fluid intake), metabolic syndromes, and significant cognitive impairment (Gormley et al., 2012). As might be expected, numerous studies have shown OAB to impact negatively on an individual's work productivity

and health-related quality of life (Coyne et al., 2011; Coyne et al., 2008; De Wachter & Wyndaele, 2003; Abrams et al., 2002).

Background and significance of OAB

The prevalence of OAB in the United States and Europe is 16% in men and 17% in women (Kannan et al., 2009). The occurrence increases with age, reaching almost 20% in both men and women by the seventh decade (Hu et al., 2003). The worldwide prevalence of OAB is believed to be between 50 million and 100 million (Benner et al., 2009) with estimates as high as 10% of the global population (Jung et al., 2012, Kannan et al., 2009).

These statistics are likely to be underestimates, since relatively few individuals with this symptom complex seek treatment. A survey of 163,000 adults 18 years or older found that over a quarter of respondents scored high on the Overactive Bladder-Validated 8 questionnaire, an outpatient bladder awareness measure, as being significantly bothered by OAB symptoms (Milsom et al., 2012). Yet, less than half of those carrying the likely diagnosis of overactive bladder syndrome had discussed the symptoms with their physician. This is especially true of women with urinary incontinence, as demonstrated by a questionnaire-based study of middle-aged women in Israel (Vinker et al. 2001). Thirty-six percent of respondents reported episodes of urinary incontinence, especially those who were older, menopausal, obese, and had coexisting conditions. Of these women, 44% stated that the symptom had a detrimental effect on their quality of life. Nevertheless, only 32% of those affected had sought advice from their doctors.

A large community telephone survey of nearly 5000 non-institutionalized adults in the United States compared the health-related quality of life of OAB patients with that of controls and found significantly lower scores on the SF-20 HRQOL index, especially with regard to such measures as health perception, role functioning and mental health (Lieberman et al., 2001).

Another investigation, enrolling 20,000 participants from the United States revealed that OAB was associated with an increase in anxiety, depression and health care usage (Hu et al., 2003). This study was part of the EpiLUTS Internet survey, which compiled data on lower urinary tract symptoms (LUTS) from the UK, Sweden and the U. S. (Chapple et al., 2005). Similarly, a report by Epstein and Goldberg (2005) revealed the significant effect that OAB can have on social interactions, sleep, depression, sexual health, and overall health-related quality of life.

It appears difficult to predict the likelihood of overactive bladder syndrome in a given individual on the basis of other existing medical conditions. A Korean study, analyzing risk factors for OAB in nearly one thousand participants, found that educational status, history of stroke, osteoporosis, asthma, rhinitis, and cataracts were significantly associated with this syndrome (Jung et al., 2012). The link between most of these attributes and OAB, however, is not apparent. There is some evidence that OAB symptoms may be influenced by cognitive status. In this regard, a recent study from the National Institutes of Health revealed increased activation of the insula and the anterior cingulate gyrus of the limbic cortex in patients with OAB (Komesu et al., 2011). The activity of these brain regions is modulated by the prefrontal cortex, the area of the brain involved with executive function and decision making.

While the prevalence of OAB in populations living in residential facilities for the elderly is quite significant, most studies of life-satisfaction in OAB individuals have focused on men and women in late middle-age, rather than on significantly older populations living at home or in a nursing or assisted living facility (Coyne et al., 2011; Coyne et al., 2008; Kannan et al., 2009; Abrams et al., 2003). In addition, surveys have generally looked only at the effect of urinary incontinence on quality of life, and have not evaluated the effects of other cardinal symptoms of OAB, such as frequency, urgency without incontinence, and nocturia. In fact, urgency, and not

urge incontinence, has been shown to most significantly decrease patient-reported HRQOL (Chapple et al., 2005) and thus this symptom must be present in order to make a diagnosis of OAB. The two questionnaire-based surveys that did evaluate the impact of urinary urgency and frequency on HRQOL did so using subject groups with mean ages that ranged from 52 to 60 (Jung et al., 2012; Tubaro, 2004) and did not include individuals in higher age brackets.

The designation of OAB is a clinical one, subject to methodological variations across studies. Such disparities make comparative studies of OAB less than definitive, since the diagnostic criteria are often not completely congruent (Chapple et al., 2005). In order to make the diagnosis of an overactive bladder, therefore, it is necessary to rule out polydipsia (self-induced excessive fluid intake) as the cause of polyuria and nocturia. These entities can be distinguished using frequency-volume charts (Stewart et al., 2003). In general, the OAB patient has low volume voids. In addition, unlike interstitial cystitis, another bladder disorder often associated with frequent urination, bladder or pelvic pain is not a frequent concomitant of OAB (Chapple et al., 2005).

In 2000, the annual costs of OAB in the U.S, including targeted medical care and treatment of related problems, the purchase of absorbent products, and expenditures for assisted living or nursing home care, were estimated to be from \$16 to \$26 billion (Girman et al., 1998). The cost is greatest among the elderly. Since it is estimated that by 2020, over 40% of the global population will be over age 65, the financial burden of untreated OAB on society will be staggering (Nitti, 2002). It is estimated that 25% of the total cost of OAB in the United States relates to the care of institutionalized patients (Lieberman, Hunt, & Stewart, 2001). Such expenditures relate to the direct cost of diagnosis, treatment and nursing care, as well as to the indirect costs associated with sleep disturbance, depression, UTIs, skin breakdown, and fractures

due to falls occurring during the frequent trips to the bathroom (Elliott et al., 2010; Brown, McGhan, & Chokroverty, S., 2000).

The Study

Purpose

The aim of this investigation is to determine the prevalence of OAB in the female population of an assisted living facility in the greater Hartford, Connecticut region and to compare the HRQOL of women who satisfy the diagnostic criteria of OAB with those who do not. Since adjustment to life in age-segregated, congregate dwellings can be difficult for elderly individuals with mental or physical infirmities (Hu et al., 2003), it is important to recognize OAB and maximize cognitive function and minimize bladder dysfunction in this segment of the population, with an eye toward encouraging increased independence, socialization, and improved quality of life. Acknowledging the prevalence of OAB among seniors might lead both to decreased morbidity from this urinary syndrome, better health-related quality of life, and less stress on an already overburdened American medical system.

The goal of this investigation is to assess the prevalence of OAB in a sample of the female population of an ALC and to determine the effect of OAB symptoms on HRQOL of women living in this setting. Several well-validated questionnaires have been used to diagnose and assess the degree and severity of urinary tract symptomatology, based on patient-reported outcomes (PROs) (Brubaker et al., 2006). It should be noted that the correlation between such subjective inventories and abnormalities demonstrable on a formal cystometric study of urodynamics (e.g., overactivity of the detrusor muscle) is only moderate (Lemack & Zimmern,

1999). However, the important metric for this study, with regard to patient function in the ALC environment, should arguably be the *perceived* effect of urinary dysfunction on HRQOL rather than an analysis of objective cystometric findings.

Hypotheses

In view of previous research that has shown OAB to impact negatively on an health-related quality of life (Coyne et al., 2011; Coyne et al., 2008; De Wachter & Wyndaele, 2003; Abrams et al., 2002), it would be predicted that subjects with higher scores on the OABSS questionnaire will evidence a lower score on the SF-20. It would also be predicted that at least some of the scores on the six SF-20 HRQOL measures will correlate negatively with the score on the OABSS.

It should be noted, however, that the evolution of the assisted-living concept has been based on the importance of autonomy and independence, factors that are maximized in assisted-living communities. These are the aspects of *aging in place* that seniors find most important (Street et al., 2007; Williams, 1991), and are the features of age-segregated residential communities that are most often associated with improved quality of life (Chapin & Dobbs-Kepper, 2001; Ball et al., 2000). Thus, it is possible that, despite significant OAB symptoms, residents of an ALC with opportunities for enhanced social interaction and health-promoting activities may be able to overcome the limitations of declining health in many spheres, including OAB, and maintain or even experience an improvement in HRQOL.

Methods

This investigation, IRB # 14-175-2, was granted approval on July 31, 2014.

Setting

The study was conducted at the Seabury Active Life Care Community, an assisted living neighborhood located in Bloomfield, Connecticut that offers home health care, assisted living, skilled nursing, visiting nurse care, and rehabilitation services to individuals age 62 and older. Living accommodations include a choice of well-appointed individual villas, cottages, and studios, and one and two bedroom apartments. Available services include biweekly housekeeping, a 20 meal/month meal program, transportation to shopping centers and physician visits, exercise classes, including dance, Pilates, Yoga, aquatic classes and prescription delivery. Personal training and nutritional counseling are available for an additional fee. Residents can obtain medical care from their own physicians or from board certified physicians affiliated with the ALC. Assisted living services are provided by the community's own Assisted Living Services Agency (ALSA), licensed by the State of Connecticut. Twenty-four hour, state-licensed skilled nursing is available, as is an on-site licensed Medicare-certified rehabilitation department. According to the Seabury on-line brochure, the community "combines exceptional residences and an independent lifestyle with the security of future long-term quality health care at virtually no additional cost" (<http://www.seaburylife.org/about>).

Subjects

Thirty two female participants were recruited from the Seabury Active Life Care Community to take part in a questionnaire survey, predominantly through presentations to the residents and recruitment by the Medical Director of the ALC. In addition, flyers describing the study were posted on the grounds (See Appendix A). Male residents were excluded for two reasons: (1) to create a more uniform subject pool with the same general pelvic anatomy (although some subjects may have had hysterectomies or other pelvic surgeries), and (2) to avoid the potentially confounding role of benign prostatic hyperplasia (BPH), contributing to a

subject's OAB-like symptom complex. BPH is characterized by frequency and nocturia, symptoms that might be difficult to disentangle from those associated with OAB syndrome (Abrams et al., 2003).

Permission to conduct the study was obtained from the Chief Operating Officer of the institution and informed consent was obtained from the subjects (See Appendix B). Individuals who were deemed mentally incompetent by the staff to provide informed consent were excluded from the study. In addition to being unable to give their permission to take part in the investigation, significantly demented residents might have a distorted sense of their well-being and body image and thus might not be able to answer the survey questions in a straight-forward and accurate way. Potential subjects were not disqualified on the basis of aphasia, as long as they were able to complete the questionnaires, with intelligible verbal responses or, preferably, in writing. Subjects who met these conditions were included in the study. With the exception of the exclusion criteria enumerated, the study population was comprised of all those who wished to participate. As noted, potential subjects were given a short presentation of the goals of the investigation and how the knowledge gleaned might help them and others in the future.

All pertinent HIPAA regulations were followed. The name of each participant was not obtained in order to protect anonymity. The subject's numerical age, however, was self-reported on the questionnaire itself. The scores on the various inventories were entered into an Excel spreadsheet. The questionnaires were administered individually to maximize privacy and confidentiality.

Variables

The questionnaire distributed to the participants was a composite of the SF-20 HRQOL (See Section entitled Health-related quality of life) and the OABSS (Homma et al., 2006)

assessment instrument. The actual questionnaire, source attributions, and scoring scales are shown in Appendix C.

The SF-20 survey contains questions measuring six different aspects of HRQOL: physical functioning, role functioning, social functioning, mental health, health perceptions, and pain. There are varying numbers of questions asked in each category, and the answers are scaled so that high scores indicate better functioning for each of the domains tested (See Table 1 for domains, number of items in each domain, and survey question numbers.) (See Appendix C for the survey questions that correspond to each number.)

Table 1. Definitions of Health Concept in SF-20 (adapted from Stewart et al., 1988)

Measure	No. of Items	Definition
Physical functioning	6 (questions 2a, 2b, 2c, 2d, 2e, 2f)	Extent to which health interferes with a variety of activities (e.g., sports, carrying groceries, climbing stairs, and walking)
Role functioning	2 (questions 3b, 3c)	Extent to which health interferes with usual daily activity such as work, housework, or school
Social functioning	1 (question 4a)	Extent to which health interferes with normal social activities such as visiting with friends during the past month
Mental health	5 (questions 4b, 4c, 4d, 4e, 4f)	General mood or affect, including depression, anxiety, and psychological well-being during the past month
Health perceptions	5 (questions 1, 5a, 5b, 5c, 5d)	Overall ratings of current health in general
Pain	1 (question 3a)	Extent of bodily pain in past 4 weeks

In the SF-20, the six item physical functioning domain assesses self-perception of physical limitations and capacities, mobility, and self-care ability (Stewart, Ware, & Brook, 1981; Stewart, Ware, & Brook, 1977). Role functioning is a two item section that measures the effect of poor health on the ability to carry out expected roles. Social functioning is assessed with a single item that centers on limitations in an individual's ability to participate in social activities due to health issues. Mental health is assessed with a five item group of questions based on the Rand Health Insurance Experiment (HIE) Mental Health Inventory (MHI) (Davies et al., 1988). The items in the Health Perceptions subsection of the survey are a subscale developed from a larger questionnaire that deals with personal awareness of one's current health status (Davies & Ware, 1981). The final question of the SF-20 asks participants to assess their level of pain from none to very severe. The survey takes, on average, ten to fifteen minutes to complete. (See Appendix C)

The OAB portion of the composite survey is based on the Overactive Bladder Symptom Score (OABSS) questionnaire. The OABSS centers on four questions, answered using a Likert scale, which focus on the frequency of urination during both evening and waking hours, the occurrence of a sudden urge to urinate that is difficult to defer, and the urinary incontinence associated with an overwhelming urge to void. The maximum possible total score on the OABSS is 15, with previous studies suggesting the ability to distinguish OAB subjects from non-OAB subjects on the basis of their respective scores (Homma et al., 2006; Abrams et al., 2003). Homma et al (2006), in developing the study, looked at 200 patients, approximately half of whom had been diagnosed with OAB, the rest assessed as having urinary symptoms due to other pathologies. They found that subjects with OAB had mean OABSS scores of 8.36 ± 3.12 , while

those with other urinary conditions, including stress incontinence and other forms of LUTS, never exceeded a mean score of 5.14 ± 2.92 . It should be noted, however, that significant overlap exists between the scores of OAB and non-OAB subjects. This overlap is intrinsic to the published diagnostic cut-offs, and reflects the absence of a strict definition of the syndrome and the difficulties in making a definitive determination of the presence of OAB using an instrument based solely on patient perception rather than on cystometric and urodynamic studies. Nevertheless, the OABSS is widely-used and well-validated (Blavais et al., 2007; Abrams et al., 2003).

Data Analysis

Scale construction for the SF-20

Prior to analyzing the relationship between OAB and HRQOL, the questions making up each of the six separate measures of the SF-20 were linearly transformed to 0-100 scales using a rubric provided by the Rand Corporation (See Table 2). This was done in order to take into account the varying response ranges for individual questions (See Appendix C, Ware et al., 1988).

$$\text{New Score} = 100 (\text{old score} - \text{lowest possible score}) / (\text{highest possible score} - \text{lowest possible score}).$$

The transformation formulas are simplified and shown in Table 2 below. The intent of the linear score transformation procedure was to make it possible to combine the items included in each of the six measures into a single score by adding the transformed scores for the items in each measure (see Table 1), obtaining the mean score for the items in the measure, adding the six subscores, and then dividing the total score (potential range 0 to 600) by the number of measures

(6) to get a final HRQOL average score, ranging from 0 to 100. As noted, the higher the score in each category (See Table 1), the greater the HRQOL assessed for that domain.

Table 2. Transforming item scores linearly to common metric with range of 0-100.
(Ware et al., 1988)

RANGE OF RESPONSES TO QUESTIONS	RECODING FORMULA	ORIGINAL RESPONSE	RECODED VALUE
1 to 2	New = 100 (Original Score Average -1)	1	0
		2	100
1 to 3	New = 50 (Original Score Average -1)	1	0
		2	50
		3	100
1 to 5	New = 25 (Original Score Average -1)	1	0
		2	25
		3	50
		4	75
		5	100
1 to 6	New = 20 (Original Score Average -1)	1	0
		2	20
		3	40
		4	60
		5	80
		6	100

New = Transformed Item Score; Core = Original Item score

The omission of an answer for the “pain” question (See question 3a, Appendix C) was interpreted as indicating “no pain.” It has been estimated that approximately 12% of respondents over age 75 omitted answers to this and other questions (Ware et al., 1988). Such occurrences were addressed in this analysis by averaging together the non-missing responses in each section, as recommended in the scoring manual (Ware et al., 1988).

Scoring the OABSS

The OABSS scoring guidelines are shown in Appendix C. Higher scores indicate a greater degree of OAB symptoms (Ware et al., 1988). As noted, the maximum score on the survey is 15, indicating the most severe degree of OAB symptomatology.

Statistical analyses

Regression analyses were performed between the Total Score on the SF-20 survey and the Sum Score on the OABSS to determine the relationship between health-related quality of life score and the severity of OAB symptoms. In this way, it was possible to assess whether there was an inverse linear relationship between HRQOL and the severity of OAB symptoms or whether there is a threshold effect, where the influence of OAB symptoms on HRQOL was only seen at OABSS scores in the higher ranges.

Additional regression analyses were done comparing SF-20 scores for each of the six separate components of the SF-20 inventory with OABSS score to determine whether there were specific domains of HRQOL (i.e., physical functioning, role functioning, social functioning, mental health, health perceptions, and degree of pain) that were more significantly affected by OAB symptomatology. Age was also regressed against OABSS score.

Results

The mean age of the 32 participants was 85.4 (range 74-100, SD 5.86). Three subjects left out answers (9%).

HRQOL Scores

The HRQOL scores ranged from a low of 23.5 to a high of 97.3. The mean score was 69 (SD 21.6), with a skew toward the higher scores (better HRQOL). The average total SF-20 scores for each measure and the associated standard deviations are shown in Table 3 below. The highest mean subscores were found in the domains of social functioning and mental health, while the lowest mean subscores were observed in physical functioning and health perceptions. The standard deviations (SD) of the scores for each measure were similar to those reported in other studies that use this HRQOL instrument (e.g., Carver et al., 1999) and indicate the wide distribution of scores. It should be noted that scores assessing HRQOL using the SF-20 are a continuum used for comparison purposes, with no specific high/low cut-offs.

Table 3. Mean HRQOL composite score and subscores.

	Physical Functioning	Role Functioning	Social Functioning	Mental Health	Health Perceptions	Pain	HRQOL
Mean	54.9	68.8	87.5	76.1	59.2	67.5	69
SD	38.7	43.5	22.6	15.8	19.2	29.1	21.6

OABSS Scores

OABSS scores ranged from a low of 1 to a high of 12. The mean score was 6.4 (SD 3.2). Ten subjects had scores ≥ 8 , putting them in the likely range for OAB, while 18 participants had scores ≤ 5 , suggesting that they would not receive this diagnosis (Homma et al., 2006). Only 4 subjects had scores that fell between the two points of demarcation, and were thus indeterminate.

Regression

There was no significant association between the OABSS score and the total HRQOL, nor was an association observed between the OABSS and the scores for any of the six individual measures of the SF-20 ($p > .05$) (See Table 4 below). Thus, increasing OABSS score did not appear to correlate with HRQOL. Age also failed to correlate with OABSS score.

Table 4. Pearson's r and p -Values for age, HRQOL, and each of the HRQOL measures as a function of OABSS

MEASURE	r and p values
Age	$r(30) = .033, p = .250$
Physical Functioning	$r(30) = -.044, p = .809$
Role Functioning	$r(30) = .026, p = .885$
Social Functioning	$r(30) = -.167, p = .354$
Mental Health	$r(30) = .092, p = .612$
Health Perceptions	$r(30) = .070, p = .700$
Pain	$r(30) = -.176, p = .328$
HRQOL	$r(30) = -.107, p = .555$

Discussion

This study investigated the effect of overactive bladder syndrome on the health-related quality of life of 32 residents of the Seabury Active Life Care Community, an assisted living neighborhood located in Bloomfield, Connecticut, using widely-used and well-validated questionnaires to assess symptoms of OAB and quantify HRQOL (Homma et al., 2006; Ware et al., 1988). Approximately 31% of residents satisfied the score criteria for OAB, a percentage in excess of the 20% prevalence reported for individuals in their 7th decade (Hu et al., 2005). The subject group's mean age, however, was 85.4 (SD 5.86) with a range of 74 to 100, and thus the individuals studied were much older than subjects from studies previously reported in the

literature. Since the incidence of OAB increases with age (Hu et al., 2003), the greater incidence of this diagnosis among participants in this investigation was not unexpected.

There was no significant correlation between the subjects' scores on the OABSS and total score on the SF-20, suggesting that, at least in this specific ALC sub-population, the diagnosis of OAB did not affect HRQOL ($p > .05$). In addition, there was no apparent effect of OAB symptoms on any of the six individual measures comprising the SF-20 ($p > .05$). These results are contrary to expectations and to the findings of a survey of almost 700 adults aged 18 to 65+ living in non- age-segregated communities around the United States (Lieberman et al., 2001). In that study, individuals with OAB evidenced decreased quality of life relative to controls without OAB. Other similar investigations have also revealed a significant negative impact of OAB symptoms on HRQOL among individuals living in the greater community (Coyne et al., 2011; Epstein & Goldberg, 2005).

The results of the present study may relate positively to the general mission and nature of ALCs and the opportunities available for social interaction at the Seabury Active Life Care Community. As noted, assisted-living communities represent the most rapidly expanding category of residential care for America's senior citizens, with an annual growth rate of 20% (Cummings, 2002). The philosophy behind the creation of these settings has been the notion that the maintenance of social support, autonomy, and independence in the face of real or anticipated physical decline will have positive effects on the physical and mental health of the elderly (Mitchell & Kemp, 2000; Kahn, 1994). The constructive social climate afforded by a well-run ALC has been found to be associated with a positive QOL and is associated with fewer symptoms of depression (Mitchell & Kemp, 2000). ALCs, by providing a milieu that encourages socialization, can promote a more positive sense of well-being across measures

of life satisfaction and quality of life (Street et al., 2007). In fact, it has been shown that the *perception* of social support correlates with life satisfaction to an even greater extent than the actual number of social programs provided by a given facility (Cummings, 2002).

It is generally agreed that successful aging depends on numerous interrelated determinants, including both physiological (health-related) and psychosocial factors (Troutman, 2011; Bowling, 2007). A study by Mitchell and Kemp (2000) found a salutary effect of the cohesive and less conflictual setting observed at several California ALCs on a sample of 201 residents with an average of four chronic health conditions on life satisfaction. In their study, social climate had the strongest correlation with measures of QOL. To a significant degree, the maintenance of an acceptable quality of life in one's later years requires *gerotranscendence*, the ability to explore a new definition of oneself and develop a self-concept that incorporates a rational approach to physical and mental strengths and weaknesses and diminishes self-occupation with physiologic and physical losses (Flood, 2006). The assisted-living environment may provide a setting that facilitates such evolution in senior adults, and may explain why, despite a significant prevalence of overactive bladder syndrome in the index ALC population studied, health-related quality of life appears to be unaffected by this condition.

Limitations

This study is not without limitations. Seabury is only one of thousands of assisted-living communities around the country. It serves a significantly homogeneous, predominantly Caucasian, geographically limited, and affluent population. In addition, the sample of Seabury residents who took part in the study was small and might not be representative of the female population residing in this assisted-living community. As is true with any survey investigation, those who choose to participate may differ from those who do not take part. Participants in this

study may have been ALC residents who were more troubled with OAB symptoms, or, conversely, individuals who were healthier and more interested in taking part in a research project that could potentially help others.

No demographic data other than age was obtained. Other individual factors such as marital status, proximity to family, level of education, and socioeconomic status might have affected HRQOL. Studies have suggested that low-income elderly individuals of color experience greater health-related functional impairment and poorer quality of life than do white, affluent seniors (Gibson & Burns, 1991). Thus, the results of this study might not be generalizable to ALCs with lower-income, ethnic minority residents. In addition, data relating to previous or ongoing medical treatment for OAB symptoms were not obtained. Medical treatment for this condition might have resulted in lower OABSS scores on the survey. Future studies should include a larger, more randomly selected population of assisted-living residents from many different communities and should obtain and evaluate more demographic and medical background information about the participants and the medications that they take which could affect urinary function (e.g., diuretics).

Finally, it should be noted that questionnaires used to diagnose medical conditions and quality of life are imperfect measures. Nevertheless, the OABSS and the SF-20 are among the most widely used and accepted inventories (Blavais et al., 2007; Stewart, Hays, & Ware, 1988) used in studies of OAB and HRQOL.

Conclusions and significance in the field of public health

Assisted-living communities have proliferated in response to the desire of senior adults to maintain social and emotional connections despite current or future infirmity, and in recognition of the relationship between social engagement and mental and physical health. Such living

arrangements appear to foster independence and autonomy, while meeting basic material resource needs and promoting better quality of life. In the senior population at large, the burden of significant medical conditions such as OAB on health-related quality of life has been demonstrated in studies using large-scale surveys. The results of this investigation suggest that living in the Seabury Active Living Community provides an environment that may obviate the impact of OAB and perhaps, more generally, the effect of other medical conditions on an individual's perception of health-related quality of life.

If larger studies confirm these findings in this and other ALCs, the implications for the development and refinement of the ALC concept are clear. The role of the ALC is to provide the material and human resources that maximize quality of life in the face of chronic disability, whether physical or cognitive. Making the possibility of living in an ALC available to a wider population of seniors, including elderly people of color or of lower socioeconomic status, may well be the best way to address the needs of our baby-boomers as they become senior Americans.

APPENDIX A

**Bothered by your urinary symptoms?
Tired of feeling like you are constantly
running to the bathroom?**



Help us understand how bothersome your urinary symptoms are to you!

**If interested in participating in a study,
contact: Allison Berken at 203-536-9185 or
email: aberken@student.uchc.edu**

APPENDIX B

Informed Consent Form

Principal Investigator (PI): Phillip Smith, M. D.

Co-Investigator(s): Allison Berken, 4th year medical student at UCHC

Title of Research Study: Overactive Bladder Syndrome in a Retirement Community/Assisted Living Population: Quality of Life

Expected Duration of Subject's Participation: 15 minutes

What Is The Purpose Of This Research Study?

The purpose of this research study is to determine the prevalence of overactive bladder syndrome in a retirement community/assisted living population. In addition, this study will explore the extent to which the frequent and often urgent need to urinate affects one's quality of life.

Why Am I Invited To Participate?

You are invited to take part in this study because we are very interested in health issues related to women of retirement age and how health impacts quality of life

How Many Other People Do You Think Will Participate?

We estimate that 25 - 40 people at Seabury will enroll in this study.

Is Participation Voluntary?

Participation in this study is completely voluntary. Before making a decision about whether to participate in this research study, please read this consent form carefully and discuss any questions you have with the researcher. You may also want to talk with family members, your primary care physician or a friend before making a decision.

You can choose not to participate. If you choose to participate in the study, you can change your mind later and stop participating. If you decide not to participate or you withdraw from the study after starting participation, your decision will not affect your present or future medical care.

How Long Will My Participation In This Study Last?

You will be asked to meet with the student investigator only once, to complete a questionnaire.

- *Survey Administration:* The study coordinator will give you an anonymous survey about your urinary functions and quality of life. You will then be asked some general questions to see how you think.
- *Risks Associated with Survey Administration:* You may feel uncomfortable answering some of the questions. There are no physical risks associated with the survey.
- *Safeguards Taken:* You may always choose not to answer a question that makes you feel uncomfortable.

What Are the Benefits Of Participating In This Study?

This research study will take a long time to complete. You will not benefit directly from the information we gather in the study, but may benefit in the future from what we learn. Other people who have the same condition may benefit in the future. There is also the possibility that no benefit will come from this study

Will I Be Compensated For Participating In This Study?

There is no compensation for participating in this study.

How Will My Personal Information Be Protected?

We will protect the confidentiality of your data to the best of our ability, but cannot guarantee 100% protection. The following procedures will be used to protect the confidentiality of your data. The study staff (principal investigator, research coordinator, co-investigators etc.) will keep all study records (including any codes to your data) locked in a secure location. All information will be placed in separate research record that is apart from your medical record. Research records will be labeled with a number and all contents of the research record will be labeled with only that number. Any computer hosting such files will also have password protection to prevent access by un-authorized users. Data that will be shared with others will be coded as described above to help protect your identity.

At the conclusion of this study the researchers intend to publish an article on their findings. Information will be presented in summary format and you will not be identified in any publications or presentations.

What Happens to the Sample if I Withdraw from the Study?

Data collected before your withdrawal from the study will remain in the research database.

What if I Have Questions?

The Student Investigator, Allison Berken, is willing to answer any questions you have about the research. You are encouraged to ask questions before deciding whether to take part. You are also encouraged to ask questions during your study participation. If you have questions, complaints or concerns about the research, you should call Allison Berken at 203-536-9185.

If you have questions about your rights as a research subject you may contact a coordinator at the Institution Review Board at 860-679-1019, 860-679-4851, or 860-679-4849.

You may also call a coordinator at the Institutional Review Board if you want to talk to someone who is not a member of the research team in order to pass along any suggestions, complaints, concerns or compliments about your involvement in the research, or to ask general questions or obtain information about participation in clinical research studies.

Please do not call the IRB number for medical related issues or to schedule or cancel an appointment.

Consent To Participation:

By signing this form you acknowledge that you have read, or have had read to you, this informed consent document, have talked with research personnel about this study, have been given the opportunity to ask questions and have them satisfactorily answered, and voluntarily consent to participate in this project as described in this form.

By signing this form the individual obtaining consent is confirming that the above information has been explained to the subject and that a copy of this document, along with a copy of the Research Participant Feedback Form, will be provided to the participant.

Participant	Printed Name	Signature	Date	Time

APPENDIX C

Age _____

HEALTH-RELATED QUALITY OF LIFE
SF-20 (from Ware et al., 1988; reformatted for this study)

1. Please put an X over the number that describes how you feel.

In general, would you say your health is:

- 1 Poor
- 2 Fair
- 3 Good
- 4 Very Good
- 5 Excellent

2. Please put an X in the appropriate bracket.

For how long (if at all) has your health limited you in each of the following activities?

	1	2	3
	More than 3 months	3 months or less	Not limited
a. The kinds or amounts of vigorous activities you can do, like lifting heavy objects, running or participating in strenuous sports	()	()	()
b. The kinds or amounts of moderate activities you can do, like moving a table, carrying groceries or bowling	()	()	()
c. Walking uphill or climbing a few flights of stairs	()	()	()
d. Bending, lifting or stooping	()	()	()
e. Walking one block	()	()	()
f. Eating, dressing, bathing, using the toilet	()	()	()

Please put an X over the number that best answers the following questions.

3a. How much bodily pain have you had during the past 4 weeks?

- 1 Very severe
- 2 Severe
- 3 Moderate
- 4 Mild
- 5 Very mild
- 6 None

3b. Does your health keep you from working at a job, doing work around the house?

- 1 YES, for more than 3 months
- 2 YES, for 3 months or less
- 3 NO

3c. Have you been unable to do certain kinds or amounts of work, like housework?

- 1 YES, for more than 3 months
- 2 YES, for 3 months or less
- 3 NO

4. For each of the following questions, please put an X in the brackets that most describe the way you have been feeling for the past month:

	1	2	3	4	5	6
	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a. How much of the time, during the past month, has your health limited your social activities (like visiting with friends or close relatives)?	()	()	()	()	()	()
b. How much of the time, during the past month, have you been a very nervous person?	()	()	()	()	()	()
c. During the past month, how much of the time have you not felt calm and peaceful?	()	()	()	()	()	()
d. How much time during the past month have you felt downhearted and blue?	()	()	()	()	()	()
e. During the past month, how much of the time have you not been a happy person?	()	()	()	()	()	()
f. How often, during the past month have you felt so down in the dumps that nothing could cheer you up?	()	()	()	()	()	()

5. Please put an X in the brackets that best describes whether each of the following statements is true or false for you (mark only one answer for each).

	1	2	3	4	5
	Definitely True	Mostly True	Not Sure	Mostly False	Definitely False
a. I am somewhat ill	()	()	()	()	()
b. I am not as healthy as anybody I know	()	()	()	()	()
c. My health is not excellent	()	()	()	()	()
d. I have been feeling badly lately	()	()	()	()	()

OVERACTIVE BLADDER SYMPTOM SCORE (OABSS) (Homma et al., 2006)

Question

	<u>Frequency</u>	<u>Score</u>
Question 1:		
How many times do you typically urinate from waking the morning to going to sleep at night?	7 or less	0
	8-14	1
	15 or more	2
Question 2:		
How many times do you typically wake up to urinate at night?	None	0
	1	1
	2	2
	3 or more	3
Question 3:		
How often do you have a sudden desire to urinate that is difficult to defer?	None	0
	Less than once a week	1
	Once a week or more	2
	About once a day	3
	2-4 times a day	4
	5 times a day or more	5
Question 4:		
How often do you leak urine because you cannot defer the sudden desire to urinate?	None	0
	Less than once a week	1
	Once a week or more	2
	About once a day	3
	2-4 times a day	4
	5 times a day or more	5

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