Bringing Mohammed to the Mountain: Educating the Community for Continence

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Just for a moment, imagine yourself planning an outing with friends. Foremost in your mind is the fact that wherever you go, you must know where and how to get to a bathroom in a timely manner. Although you would love to wear a brightly colored spring ensemble, you know you will choose from the entire wardrobe of black in your closet. If you go to the theater, you will need a seat on the aisle with an easy escape route to the bathroom, which you will plot in your mind before you even sit down. You don’t really go out much anymore with friends for this very reason. This is your life. You feel isolated and alone and don’t really believe there is any help or, more importantly, any hope. For millions of Americans, this scenario is their reality, but it does not have to be this way.

A recent survey reported that 32% of men and women ages 30 to 70 have experienced some degree of bladder control loss, and 87% of the people who have experienced loss of bladder control are not diagnosed (Medical Week Staff, 2004). The survey also reported that those adults who were diagnosed waited approximately 6 years after first experiencing bladder problems to seek help from a health care professional. One of the best ways to promote awareness and encourage people to seek help is through continence education. Educating people about incontinence is empowering. It sends the important message that people with incontinence are not alone and that often there is help and hope for resolving the problem.

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The Challenge of Education For Continence

Health educators, the majority of whom are nurses, are well aware of the incredible sense of satisfaction that comes from providing new information to a patient who then turns that information into an action plan which changes his or her life. One of the most dramatic demonstrations of the effect of health education can be seen when individuals with incontinence learn about the gamut of solutions now available for loss of bladder and/or bowel control. Many people who discover that something can be done about their incontinence (improved with medications or exercises, cured with surgery, or managed with a product that allows the user to become “socially continent”) rapidly discard their self-inflicted social isolation. Like magic, they have been released from the impact of a symptom that brought their lives to a screeching halt and caused them to spend years hiding at home tethered to a toilet rather than face the social stigma and personal embarrassment of being wet in public.

The astronomical loss of human potential, for example the volunteer power the baby boomers can provide, coupled with family stress and other associated outcomes caused by incontinence, is incalculable. Just a few short years ago, these social and personal costs might well have been attributed to untrained and unknowledgeable health professionals, or to the lack of products and devices for management. Today, however, under-reporting and under-treatment must be laid squarely at the doorstep of education and motivation (for example, the lack of awareness regarding the variety of help and hope available in 2006), and exactly where to find...
Professor Christine Norton, PhD, RN, the Continence Promotion Committee of the International Continence Society which meets annually to share information, and the Continence Foundation for Continence to decide, as the saying goes, “If the mountain will not come to Mohammed, Mohammed will go to the mountain.”

About The Simon Foundation for Continence

The Simon Foundation for Continence is the oldest patient-led, not-for-profit, advocacy organization for individuals with incontinence. Its mission is to “bring the topic of incontinence out of the closet; remove the stigma associated with incontinence; and provide help and hope to individuals with incontinence, their families, and the health care professionals who provide their care.”

In the summer of 2003, the Foundation launched its 3rd decade of service and announced several new long-term projects as part of a new decade’s strategy to promote continence. Included among these initiatives are two inter-related programs, the Bladder Health Mobile and the Defeating Stigma in Healthcare program (in 2004 the Society of Urologic Nurses and Associates was the first organization to receive a Defeating Stigma in Healthcare Award in the medical organization category).

The idea of promoting continence with a Bladder Health Mobile stems from the experiences of Simon’s Founder, Cheryle Gartley, who for over a period of many years has listened to the challenges of several leaders of similar not-for-profit organizations promoting continence worldwide. (Ms. Gartley co-founded with Professor Christine Norton, PhD, RN, the Continence Promotion Committee of the International Continence Society which meets annually to share the challenges and successes of continence education.) The concept of using a travelling exhibit to promote continence is a response to the theme she observed across every culture — the inability to reach a large proportion of the population with the symptom of incontinence.

The Bladder Health Mobile (BHM) project is quite literally an attempt to take Mohammed, or in this case the bus, to the mountain. It is an innovative idea to elevate the stature of bladder-related conditions, remove the stigma surrounding misbehaving bladders, and provide public awareness and education at the community level about all bladder-related conditions. Education about incontinence and overactive bladder will, of course, be at the heart of this endeavor.

The Bladder Health Mobile Concept

For the last 20-some years, not-for-profits, as well as corporations marketing incontinence products, medicines, and devices have worked diligently to reach the millions of Americans who live with misbehaving bladders. Although much has been accomplished, the fact remains that all too many patients are not seeking or finding help. It is time for new and innovative methods to increase public awareness of all treatment options (biofeedback, Kegel exercises, sling procedures, and artificial sphincters, to name just a few that are not advertised nightly on the television networks) not only to inform, but equally important to create hope. Furthermore, these resources should be within easy reach of those individuals whose lives are still being destroyed by incontinence.

The purpose of the BHM project is to provide a solution which will:

• Provide education.
• Increase public awareness of incontinence and other bladder conditions (interstitial cystitis, urinary tract infections, bladder cancer, and related conditions such as fecal incontinence).
• Facilitate dialogue between consumers and their health care professionals.
• Promote early diagnosis and proper treatment.
• Alleviate the stigma associated with bladder conditions.

Originally the vehicle that was intended to house this project was modeled upon the mobile coaches from public libraries that tour local communities and are familiar to most Americans. We anticipated equipping a Class A motor coach to visit venues such as medical institutions, shopping malls, large drug stores, libraries, schools, assisted living and other facilities that focus on the older American, to name just a few.

Imagine a high-impact coach uniquely painted (with a misbehaving bladder perhaps) crossing the highways of America. De-
pending on the size of the community, its arrival would certainly create quite a stir. This is exactly the effect hoped for to attract media coverage, an important element of this educational campaign. However, when the Foundation’s President and Director of Special Projects approached several corporations to gather support for the Mobile, two queries were consistently raised by incontinence industry executives. The first was the unavoidable high cost of liability insurance for a vehicle that the public would board. The second was doubt that Americans were ready to admit their interest in bladder health and climb aboard such a vehicle, possibly in full view of friends, neighbors, or relatives.

Given this valuable input, the BHM concept was adjusted very slightly so that a high-impact cargo van (again uniquely painted to draw attention) would deliver an extensive exhibit which would then be off-loaded and free-standing. The Foundation also began to gather information on exactly how welcome a Bladder Health Mobile would be throughout America. Over the past months we have displayed the Bladder Health Mobile and Exhibit materials at trade shows, talked about the project during keynote speeches, and provided information on the Foundation’s Web site (www.simonfoundation.org).

Nurses, physicians, and even patients throughout the United States have not only invited us into their communities, but have offered to spear the endeavor by volunteering to chair the BHM Welcoming Committee in their town or city. The following are just three examples of the type of response we are constantly receiving about this project.

“I contacted you in 2003 regarding having the Bladder Health Mobile visit our area,” wrote Judi Dunn, RNC, of Albany, NY, in December of 2005. “We have expanded greatly since our last contact and are planning to move into a new facility next month. I hope plans are coming along. I reviewed your Web site and it does appear you are getting closer to starting. I just wanted to update our address and hope you will continue to consider our location when the time arrives.”

“I am Nurse Health Educator and Chronic Care Improvement Project Coordinator for Security Health Plan,” wrote Batyah Raphaelle Grande, BSN, RN, from Marshfield, WI. “We are discussing ways to raise awareness within the community so that there will be less of a stigma associated with seeking treatment for UI. The Bladder Mobile sounds like it is a wonderful way to accomplish this. I would like to collaborate with the Marshfield Clinic in facilitating the Bladder Health Exhibit coming to our area. I am wondering if you will be coming through our area, and if so, when? Also, what preparation would we need to do in advance of your visit?”

“I am just wondering about the Bladder Health Mobile and if you would let me know of the possibility of doing this in our community,” wrote Elaine Tillman, the Wish Coordinator and Community Resource Specialist from Springfield, MO. “Do you know of any resources where individuals could get slightly damaged incontinence pads? This is such a big issue and the cost is too high for some. I have seen some single mothers who care for older children using rags because they do not have the funding to get these items. These are the people that fall between the cracks.”

“I am a patient at the Family Health Center of Wyckoff Hospital in Brooklyn, NY. I believe the Bladder Health Mobile Exhibit would benefit many consumers besides myself. I just cancelled a procedure I was to have because I was scared after researching my condition and learning what complications may result from having the operation. There are too many questions to answer before I let a doctor cut me. I am also new to this condition and I am not sure what other alternatives I have. Having the Bladder Health Mobile Exhibit available instead of having to make a dreaded doctor appointment would be helpful. Introducing some of the health experts in the community to begin a dialogue with them besides just my doctor would give me a greater chance to get all my questions answered as well as a different opinion. Please consider contacting the above hospital to see if there is a possibility you can assist their patients in becoming more educated with bladder conditions. If possible, I would like to be informed when you would be available if they accept your invitation.”

Statements such as these, coupled with a list of nurses and others who have committed to hosting the BHM while visiting Simon’s exhibits at medical meetings, emphasizes the enthusiasm awaiting the arrival of this exhibit throughout the country.

Examining the Content Of the Bladder Health Exhibit

The goal of the BHM exhibit is to offer a wide array of educational information in a variety of formats. Exhibits cater to all learner styles and are designed to ensure consumers obtain the desired information in a manner and setting that is comfortable to them. The Bladder Health Mobile Exhibit will feature the following five areas: (a) answer area, (b) product displays and audiovisuals, (c) educational materials (nonprofit produced), (d) educational materials (industry produced), and (e) health/attitude survey (see Figure 1).
One of the most unique aspects of this project is the answer area. This area will be staffed with local health professionals who will interact with visiting consumers and answer their bladder-related questions. This area of the exhibit will be designed to allow privacy when necessary and is perhaps the most important part of the entire exhibit. Extensive patient feedback from people who have attended the Foundation’s “I Will Manage” program, a professionally led, community-based educational/self-help program, has proven that one of the most important things patients wanted when attending these meetings was the opportunity to meet and ask questions of local health care providers in a stress-free environment.

The ability for patients to receive answers to their numerous questions at the BHM exhibit may well be the most valuable opportunity this public service endeavor offers. One of the strikingly consistent comments on the “I Will Manage” feedback reports, from the health professionals who are giving the lectures at the program, is their shock at how long class attendees often remain following the lecture for a chance to ask their personal questions of the nurse or doctor. In fact, we often hear complaints from the “I Will Manage” speakers that being detained after the program has caused bladder problems of their own!

The recent explosion of Internet Web sites providing information about various health topics, advertisements disguised as editorial copy, and network news reporting conflicting results from medical research have all contributed to a population that is in desperate need of spending more time with nurses and doctors whom they feel they can trust. This is happening just...
at a point when the health care system pressures leave nurses and doctors with less and less time for patient education.

In the area of incontinence, like many other urologic disorders, finding an appropriate doctor or nurse who is interested and knowledgeable regarding the patient’s condition (depending upon the community) is yet another difficult obstacle to obtaining care. Therefore, included in this section of the exhibit will be a handout containing a multidisciplinary referral list (compiled by the local BHM Welcoming Committee) of local community specialists who treat bladder problems and have expressed a desire to be listed. A disclaimer on the list will clearly tell potential patients that these health professionals have self-identified and a preface to the list will make suggestions as to questions a new patient should ask when deciding which health care professional to consult.

Product displays and audio-visuals. This portion of the center will feature audio-visuals, such as videos and DVDs covering a wide array of bladder health related topics such as interstitial cystitis (IC), bladder cancer, urinary tract infections, and enuresis, in addition to incontinence. Regarding incontinence education, one of the highlights in this section of the exhibit will be a display of the various devices and different types of absorbent products, both disposable and reusable. Many individuals are unable to try a product they see in the retail store because they are uncertain exactly what is in the package, and they do not have the financial means to gamble that what’s inside the package might fit or have enough absorbency for their particular problem. A large display board with products attached will allow visitors to touch, compare sizes, and in general become familiar with the variety available. An accompanying booklet will explain in generic terms the attributes of each category of products.

Educational materials (non-profit produced). It is important to many individuals that the content of their education is produced by organizations that do not endorse any particular treatment modality or product. For this reason, we have separated the take-home educational materials into two sections, those produced by non-endorsing entities and those provided by industry. The nonprofit section will feature materials already available from various nonprofit health advocacy organizations. A broad coalition of nonprofit organizations has agreed to provide high-

Figure 2.
Bladder Mobile

Help The Bladder Health Mobile Make Headlines In Your Community

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quality educational materials on various topics including bowel incontinence, which so often is present with bladder control problems.

**Educational materials (industry produced).** This section of the exhibit will feature materials clearly marked as developed and contributed by industry members who have donated both brochures and financial support to help make the project to raise awareness and education about specific treatments and products is a very important component of consumer education. Offering industry-provided materials also allows consumers information about how to reach representatives of companies that manufacture the products and devices in order to ask their product-related questions.

**Health/attitude survey.** The exhibit will also provide a quiet place where visitors will be asked to fill out a brief health/attitude survey. One of the weaknesses of many not-for-profit programs (the Simon Foundation included) is the ability to fund measurement of the effectiveness of their educational outreach. Working with the New England Research Institute, we intend to develop an interactive computerized exit interview questionnaire to measure the effectiveness of the information being given and to constantly improve upon the content of the exhibit.

**Tandem Community Health Promotion Opportunities**

The Bladder Health Mobile and exhibit is designed to be a catalyst to raise awareness and increase knowledge about “misbehaving bladders” within every community the exhibit visits.

The vehicle delivering the exhibit is intended to help focus media attention on its arrival (see Figure 2). One month prior to the BHM’s arrival in the community a media kit will be mailed to local media. It will explain the concept of the BHM and the educational resources that will be available at the exhibit. The kit will also contain the vehicle’s itinerary while in the area and contact information for the local Welcome Committee. In addition, this media kit will also include short educational articles to promote bladder health and reduce the stigma which is associated with the bladder.

Print-on-demand technology allows the creation of one four-color template and the ability to customize promotional pieces for each city. These materials will be distributed through health practices, hospitals, continence clinics, pharmacies, and other appropriate locations.

Although the BHM will only be in each location for a few days, we anticipate that the local Welcome Committee will use this opportunity to focus community attention on the bladder for some period of time, with continuing hospital-based lectures on subjects such as bladder cancer and urinary tract infections. A turnkey continence education program, “I Will Manage,” is also available to provide further community education about incontinence.

**A Word about Defeating Stigma**

Stigma is defined as the recognition of difference based on some distinguishing characteristic or “mark” and a consequent devaluation of the person. Stigma in health care is, of course, a subset of stigmatization in society. It is personally, interpersonally, and socially costly. It is intrinsically apparent that the scope of the problem of stigma in health care is enormous. In the United States, there are over 43 million individuals with a disability, 14.3% of the entire population, America’s largest minority. Many people living with a chronic disease or a symptom such as incontinence experience several of the components of stigma: insensitive language such as “crippled” or “birth defect,” the stress on able-bodied family members, the dilemma of passing (the ability to hide a health problem which is not immediately distinguishable), the loss of freedom in public (due to being accosted by curious strangers asking questions of a private nature), and staring (which robs one of the ability to enter into the world with the same anonymity as those who are able bodied). It will probably not come as news to many readers that doctors and nurses often “pick up” the stigma which is “assigned” to the patient population for whom they provide care. However, to the layman author of this article, there was shocked silence when a nationally prominent physician stated that he is often asked if he graduated at the bottom of his medical class, or when he is going to become a “real” doctor, due to his devotion to helping the developmentally disabled.

Defeating stigma in health care may simply begin by increasing public awareness of the enormity and impact of the problem, acknowledging that being stigmatized lessens the quality of life of millions of Americans; making a concerted effort to help individuals and their families to increase their coping skills to deal with this challenge.

The BHM is designed to play a significant role in shining a very bright light down the dark tunnel of public ignorance, which is the root cause of stigmatization. Even the humor (hopefully done tastefully) that will certainly be put forth by various journalists throughout the country may help to draw attention to how society behaves when addressing misbehaving bladder issues.

The shifting of society norms in the past not only offers hope for the acceptance of the Bladder Health Mobile project but also for...
each of our futures no matter what health challenges may befall us. For instance, just a few short years ago, being diagnosed with cancer was something to keep hidden for fear of consequences such as job discrimination and social ostracism. Today even some of our automobiles wear pink ribbons to highlight the fight against breast cancer, and we walk through a life-like portrayal of the human bowel in an exhibit traveling the country to bring about awareness of colon cancer.

The challenge of attacking stigma in health care is exciting because it has the potential to set millions free from the impact of stigma. But who will speak for Americans with health challenges; if not you, then who; if not now, then when?

Mighty Oaks from Little Bladder Mobiles Grow

It is possible to envision a world where we have defeated stigma in health care and that we will no longer need to worry about the shame, embarrassment, and stigma which surrounds the bladder, a rather small muscle with a very big impact. But today it is important for the basic messages this exhibit delivers to be heard.

- The bladder is an important organ within the body.
- The stigma surrounding the bladder and other health care issues can be removed.
- There are preventative measures to avoid many bladder conditions.
- Healthy bladder habits are one key to continued good health.
- Report bladder problems to your nurse and/or doctor.

There are many potential stakeholders in seeing that the above messages become well known to the American public (for example, Society of Urologic Nurses and Associates; American Urogynecological Society; American Urological Association; Association of Continence Nurses; American Geriatrics Society; American College of Obstetricians and Gynecologists; Wound, Ostomy, Continence Nurses; Interstitial Cystitis Association). The broad ultimate aims are ones we all share.

- Increase, on the individual consumer level, knowledge of the bladder and its attendant issues, such as incontinence, overactive bladder, bladder cancer, interstitial cystitis, and urinary tract infections.
- Increase knowledge, on both the consumer and the provider levels, of current products and treatment options.
- Build the capacity of health care professionals to respond compassionately and with appropriate knowledge to patients presenting with bladder-related symptoms.
- Increase public awareness of incontinence as a serious, but treatable health issue and help reduce the stigma associated with bladder conditions.

Looking to the Future

Some of the very first supporters to contact the Simon Foundation for Continence in 2003 when the BHCM concept was announced continue to ask “Where is it?”, perhaps impatient because they are unaware that building this project was expected to span a decade. The answer is, “It’s in the minds and the hearts of an ever-increasing number of very committed individu-