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**IMPROVING ACCESS TO INCONTINENCE AT IN
DEVELOPING AND RESOURCE-CONSTRAINED COUNTRIES**

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Key Words

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Abstract

Incontinence, as opposed to other disabilities in need of AT, is hidden, silent and much more shameful. Recent research in Canada has documented just how under-reported and managed both urinary and fecal incontinence remains exerting huge social and economic pressures on the affected individuals, their families and society as a whole. Almost 9% of the world's population suffers from incontinence making it, if it were a country, the third largest in the world. Reported prevalence may differ by country, population or region but incontinence is a global health issue. The barriers to access to incontinence AT has been documented for developed countries and the barriers to access to healthcare generally has been documented for low-income countries but access to AT for incontinence in low- and middle-income countries has not been examined to date. This paper attempts to close this gap in knowledge as yet another piece in the AT puzzle being assembled by the GReAT Consultation. This paper also calculates a conservative return on investment if incontinence was properly managed in developing and resource-constrained countries.

INTRODUCTION

Incontinence is not a single disorder but a symptom of a family of related conditions with different etiologies; it is chronic and carries an enormous stigma. Despite what many think, incontinence is not a normal part of the aging process; incontinence is usually a result of a combination of pathologic, physiologic and pharmacologic factors. In few medical areas is so much known, so much misunderstood, so little spoken, and so little done. To improve continence care anywhere does not require investigative or developmental prowess but a simple, concentrated effort to diffuse existing knowledge to close the knowledge gaps, both at the healthcare provider and patient level, in simplified layperson's language.

Incontinence, as opposed to other disabilities in need of AT, is hidden, silent and much more shameful. Recent research in Canada documented just how misunderstood, under-reported and unmanaged both urinary and fecal incontinence remains exerting huge social and economic pressures on the affected individuals, their families and society as a whole. (1) Incontinence has a negative impact on quality of life and often leads to disturbed sleep, loneliness, stress, isolation and exclusion from mainstream economic and social activities including education and employment. Co-morbidities often include skin irritation and breakdown with related infections, asthma, diabetes, high blood pressure, bladder or prostate cancer, depression, and neurological conditions. (2)

Almost 9% of the world's population suffers from incontinence making it, if it were a country, the third largest in the world yet it is almost totally ignored by healthcare providers, leaders and investigators leaving patients to suffer in silence and embarrassment preventing them from fully realizing their potential. There is no evidence to suggest that the prevalence differs by arbitrary country boundaries, populations or regions – only by gender and age with incontinence being more prevalent amongst women (14%) than men, and more amongst seniors over the age of 65 (12%). (3) Although many individual country statistics are not available, and those that are available are debatable because of inconsistent definitions and methodologies used, for some developing countries the prevalence of incontinence may need

to be adjusted downwards to account for lower life expectancies, or upwards because of gender ratios.

The barriers to access to incontinence AT have been documented for developed countries (4) and the barriers to access to healthcare generally has been documented for low-income countries (5) but access to AT for incontinence in low- and middle-income countries has not been examined to date. This gap in knowledge is another piece in the AT puzzles being assembled by the GReAT Consultation.

This paper's objectives were to (i) extrapolate from the literature a framework of barriers to access to incontinence AT in low- to middle-income countries; (ii) quantify the social and economic benefit from addressing those barriers; and (iii) recommend action steps by which those barriers to access may be overcome and patients receive the AT they need.

APPROACH/METHOD

With an extensive network of colleagues world-wide the authors have over the years researched and written extensively – both qualitatively and empirically - about the barriers to access to incontinence AT. They have successfully influenced healthcare curricula, industry practices and government policies although much remains to be done. One of the studies published in *Public Health Research* won the 2019 award for best contribution to public health knowledge.

The barriers to healthcare products in low-income countries has also been researched and documented by the collaborator and his research team. Cost, education, and supply chain security and management will all be considered along with infrastructure issues such as potable water and lavatories for hydration and hygiene.

The authors reviewed the literature on access to extrapolate a framework of access issues regarding AT and incontinence in low- and middle-income countries. This, in turn, was used to develop solutions and an action plan. The original economic analysis was conducted by the authors to quantify and monetize the benefits of taking action.

FINDINGS

1) Continenence care in developed countries: patient needs, barriers to access to AT, and solutions

In developed countries there are often gaps in healthcare funding, and continence is one of the conditions that often fall into those gaps. In Canada, for instance, 38% of Canadians have no group insurance health coverage, and in 2015 over 180,000 Canadian households mortgaged their homes to cover unaffordable healthcare costs. To use a term that has been often used in the US, there is a “doughnut hole” in health insurance and government assistance – a segment of the population left without coverage or support. (6) For the incontinent population with scarce personal resources this includes:

- individuals/families with high out-of-pocket expenses relative to their income (especially seniors living at home with an average combination of government pensions);
- people not covered with private health, medical or disability insurance and/or whose insurance does not cover continence products;
- those who work seasonally, part-time or are self-employed;
- individuals/families who may not be eligible for private or supplemental insurance;
- people with high drug costs in addition to other product costs such as continence products;
- those with a significant loss of salary due to their irresolvable incontinence.

In Canada, incontinence costs Canadian employers over 11.5 million person-days of lost work, and over \$2 billion in lost productivity. On a yearly basis incontinence adds \$3.8 billion to health care costs nationally. In total, incontinence costs Canadians nearly \$8.5 billion annually. (7)

In Ontario alone – Canada’s largest province by population with just over 14 million people - the funding shortfall was nearly \$1 billion with about one-third of that borne by individuals living at home and two-thirds living in long-term care facilities. The average senior

suffering from incontinence living at home in Ontario pays out-of-pocket \$1500-\$2250 on continence supplies – up to 10% of their income. (8)

2) Healthcare in developing/resource-constrained countries: patient needs, barriers to access, and solutions

The heterogeneity and non-standardized nature of the small number of epidemiological studies of incontinence in the developing world does not provide a reliable estimate of the prevalence of incontinence. For example, in single studies the prevalence of just urinary incontinence (UI) ranged from being 2.8 in Nigeria (9) to 57.7 in Iran. (10) Different definitions of UI, under-reporting in some cases due to the stigmatization of those suffering from incontinence, and inconsistent stratification and representation of populations studied confound these findings. Despite these study flaws, however, it cannot be denied that incontinence is as much of a problem for people living in developing countries and countries that are resource-constrained as it is in the developing world.

In recognition of this, in 2016, WHO launched its Priority Assistive Products List (APL). In the discussion leading up to the approval of the APL it was recognized that incontinence can be as disabling as not being able to walk; for many suffering from incontinence without AT, they cannot leave the house. Incontinence is also a major contributor to the increased risk of falls amongst the elderly. Incontinence has been considered by WHO as a mobility issue. For this reason the APL includes absorbent incontinence products and pads. (11)

However, 90% of those in need of these AT products cannot access or afford them. (12) Amongst the developing countries of the world the average GDP per capita is approximately \$1200, literacy rate is 74% (lower for women than men) and life expectancy is 63 years. For the 50 least developed countries comparable figures are \$300, 52% and 50 years respectively. But poverty is not the only barrier to access of AT. In many of these countries there is little or no rule of law, human rights are violated, corruption is rampant, infrastructure is minimal and healthcare nominally or not at all state financed. NGOs and third party programs often fail to

deliver healthcare because their supplies never leave the ports, are stolen and sold on the black market locally and globally, and/or health human resources and supply chain planning are inadequate/non-existent on the ground. (13)

There is no scientific evidence that patents or prices are major barriers to market access, or causatively associated with worse health outcomes, in developing and resource-constrained markets. Almost all drugs deemed to be “essential medicines” by the World Health Organization are off-patent and available as generics yet one-third of the world’s population does not have access to essential medicines. The real barriers to access in these countries are money, power, politics, and ideologies, which manifest themselves in market failure, corruption, and the lack of political will to create stable, ethical, and law-abiding government administrations that will ensure products arrive where they are destined without delay, diversion, theft, or unnecessary tariffs. There is a need for infrastructure, roads, communications, health human resources, provider compliance, patient adherence, political stability, and professional regulatory structures and protections. Enhanced state capacity to serve indigenous populations and the rule of law are integral to promoting global health and healthcare, in which AT plays a vital role. (14)

As a result there are over 150 public-private partnerships to improve access to medicines in the least developed countries; 90% having been industry-led. Together they have treated a billion patients with ten billion doses of medicine, and trained 350,000 health personnel in primary healthcare.

Notwithstanding all this, incontinence is seldom, if ever, a topic at the health and development table because it is invisible, greatly stigmatized, and is not directly life-threatening. However, lessons can be learned from the drug industry’s experience in developing countries. Provision of AT products at low or no cost is important but so are training in assessment, fitting, user adherence and follow-up. Industry assistance in this regard, working with nurses and basic health service providers at the community level, could expedite

these elements, simplify procedures, and build capacity. Good practice guidelines already exist and need only be modified to recognize cultural, social and religious needs.

DISCUSSION

Continenence care in developing/resource-constrained countries: costs, benefits, and return on investment

The Commission on Intellectual Property Rights, Innovation and Public Health has declared that all governments have failed in addressing poverty and health in developing countries. According to the World Bank the real threat to developing countries today is not environmental degradation – although very real – but poverty. Open markets, economic growth and education (especially female literacy) go hand in hand but the 10% of the developing world’s population suffering silently with incontinence need not wait for this generational shift to better manage their symptoms. Evidence from developed nations as well as evidence from developing countries has shown that centralized government bureaucracies are also not the answer but decentralized systems wherein competition is allowed. The provision of continence AT is a case where public-private partnerships will probably have the greatest results. (15) Industry members in collaboration with NGOs such as the World Federation of Incontinence Patients would be an example.

There are many treatment and management options for urinary and fecal incontinence including surgery, medication, exercises, prompted voiding and lifestyle/environmental changes but the first line of management is the availability and use of appropriate pads – a simple, relatively inexpensive AT option which is not readily available to most patients in resource-constrained countries. When appropriate absorbent continence AT is used 95% of patients report improvement in their quality of life; when AT is appropriately chosen and fitted 38% of users experience less leakage; and 47% have a reduction in skin irritation and infection. (16) With over 300 million people living on less than \$1 per day patients suffering from incontinence in the poorest of countries cannot afford even this AT.

This situation is further complicated by decision-taking around the supply and use of disposable versus reusable absorbant products. Disposable products are cheaper per item – which is good for the populations under discussion - but would require a continuous supply chain (most difficult under the above circumstances) as well as garbage collection and disposal the likes of which many in developed countries take for granted but which is all but non-existent in the poorest of countries. On the other hand, reusable products are more expensive for good quality but require abundant supplies of clean water for laundry and associated hygiene.

In a public-private partnership industry can provide financial aid, products and expertise to humanitarian, government and public health providers. Through industry-provided education, training and awareness programs and technical support health system infrastructure can be reinforced and capacity built. Potable water is also necessary for proper hydration (a key factor in continence) and proper hygiene to reduce infection. Ideally, a user-centred approach can be collaboratively developed to ensure that patient needs are recognized and products not just made physically accessible and affordable but culturally appropriate. (17)

Focussing on the 50 least developed countries (18) with a combined population of 700 million people and an average GDP/capita of \$280 a simple ROI can be calculated assuming: no cost of AT to the user/patient; a lower incontinence prevalence rate of 5% given the lower life expectancies amongst these countries; that those with incontinence are 30% active in the economy; and that 90% of the incontinent population cannot afford AT (see Figure 1). With absorbent continence AT being supplied these 31.5 million people will now be able to fully participate in society and increase the GDP of these nations overall by 3.2% or \$6.3 billion.

Figure 1: ROI on the Provision of Free Incontinence AT in the 50 Least Developed Countries

Total population (2004) of the 50 least developed countries	700 million
Total GDP (2004) of the 50 least developed countries	\$196 billion
Average per capita GDP of the 50 least developed countries	\$280
5% prevalence rate for incontinence in the 50 least developed countries	35 million
90% of those with incontinence cannot afford AT	31.5 million
GDP/capita for those with incontinence at 30% participation rate	\$84
GDP per capita lost due to incontinence	\$196
GDP regained by full participation of people with incontinence accessing AT	\$6.2 billion
% increase in GDP with full participation of those with incontinence	3.2%

RECOMMENDATIONS

Continence care for 10% of the world's population is integral to supporting the human right to live an independent life, the right to universal healthcare, and the right to fully participate in a sustainable world.

Much of the work remains to be done to place incontinence alongside other disabilities managed by AT. A standardized multinational population study would be ideal for high-level continence AT policy development across the developing world. But that is an academic desire; there are very real, practical considerations that can and must be addressed immediately.

For both disposable and reusable incontinence AT, the barriers identified and the means by which to overcome them are similar to that encountered by other widespread disability-AT pairings in resource-constrained countries.

1. **The findings above should be incorporated into a wider system of universal public health to address needs that apply to large affected populations around the world as opposed to the more targeted programming required in other circumstances.**

The greatest barriers of awareness and education, while never simply overcome, have been shown to be surmountable if key opinion leaders are given the right information and shown how to act on the problem. The stigma attached to incontinence, often reinforced by strong historical, cultural, religious and gender traditions and stereotypes, and the subsequent unwillingness to-date of authorities almost everywhere to recognize the problem and deal with incontinence can be overcome.

2. **De-stigmatizing incontinence with the facts, and educating healthcare providers as well as patients and their families on how best to manage incontinence without embarrassment will allow affected individuals to become productive and fulfilled members of their societies.**

3. **Minimal cost of absorbent continence AT, education, and supply chain security and management along with infrastructure issues such as potable water for hydration and lavatories for personal hygiene are all instrumental to improving quality-of-life for those suffering silently with incontinence.**

The AT required is theoretically readily available to all and, although expensive for the individual, is comparatively quite affordable at the system level on a continuum of low cost to high cost AT. Strategies from the biopharmaceutical industry where public-private collaboration is used can play a role in making AT affordable and accessible to all in need as a part of essential and universal healthcare.

A world where everyone with incontinence has access to quality, affordable assistive products to lead a healthy, productive and dignified life is attainable. Whether in developed or developing countries, where surgery or medication is not indicated, there is a low-tech solution to a problem plaguing hundreds of millions of women as well as men. The opportunity to have a positive impact on a large scale is inherent in making AT accessible and affordable to almost 10% of the populations of low- and middle-income countries. The improvement of the health and social well-being of large numbers by a single programme is exciting.

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