Global Forum: Spine Research and Training in Underserved, Low and Middle-Income, Culturally Unique Communities: The World Spine Care Charity Research Program’s Challenges and Facilitators

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The World Spine Care (WSC), established by volunteers from 5 continents, is dedicated to providing sustainable, evidence-based spine care to individuals and communities in low and middle-income countries consistent with available health-care resources and integrated within the local culture. The research committee approves and oversees the WSC’s collaborative research and training projects worldwide and serves to create a sustainable research community for underserved populations focused on preventing disability from spinal disorders. The purpose of this article is to describe 4 projects overseen by the WSC research committee and to discuss several challenges and specific facilitators that allowed successful completion of initiatives. These novel projects, which involved establishing spine surgery expertise and data collection in the WSC clinics and surrounding communities, all met their aims. This was achieved by overcoming language and resource challenges, adapting to local customs, and taking time to build mutual respect and to nurture relationships with local investigators and stakeholders.

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Spinal disorders, especially back and neck pain, are recognized as major public health issues in developed countries. Recently, the World Health Organization (WHO) Global Burden of Disease study highlighted that spinal disorders also place a substantial and increasing burden of disability on people living in low and middle-income countries. In 2015, the World Bank defined low-income economies as those with a gross national income (GNI) per capita of ≤$1,025, lower middle-income economies as those with a GNI per capita between $1,026 and $4,035, and upper middle-income economies as those with a GNI per capita between $4,036 and $12,475. However, knowledge about the etiology, management, and prognosis of people having these disorders is sparse in low and middle-income countries. This gap in our understanding seriously reduces the ability to address these problems and emphasizes the importance of conducting research to guide clinical care and the necessity of making advanced training opportunities available in countries where financial resources and cultural considerations are considerably different from those in higher-income and developed countries.

Despite the substantial burden of spinal disorders in low and middle-income countries, until recently, to our knowledge, there were few if any spine care organizations or charities with the ability to direct research into the unique cultural factors that may impact spinal disorders in low and middle-income countries. Without such research, embedding sustainable health-care services in local communities to address these problems is untenable. Rather, assistance for people with spinal disorders in low and middle-income countries has generally consisted of short-term mission trips by surgeons, chiropractors, physiotherapists, other clinicians, and individual researchers completing brief, directed, independent research projects. What has become clear is that there is a lack of a sustainable evidence-based model of care that includes a dedicated clinical and research infrastructure.

The World Spine Care (WSC) charity was created to bridge this gap in low and middle-income countries aiming to lessen the burden of spinal disorders. The WSC (http://www.worldspinecare.org) is a nonprofit, charitable organization that obtained 501(c)(3) tax status in California, the United States, in 2009, in Canada in 2012, and in the United Kingdom in 2016. The WSC was established by a team of volunteers and institutions from multiple countries on 5 continents who provide time, clinical and research expertise, support, and transfer of knowledge. The priorities for the WSC are to ensure that its clinical programs are evidence-based, acceptable to local communities, sustainable, consistent with available health-care resources, and integrated with local cultural traditions while avoiding the pitfalls of spine care that have emerged in high-income countries.

Purpose
As the WSC clinical team oversees daily clinical operations including patient care, the WSC research committee oversees research and training projects (Fig. 1). These projects are conducted in collaboration with researchers, clinicians, and graduate students from several institutions and countries. The goals of the research committee are to create a research community in underserved populations, to increase interest for spine research in low and middle-income countries, and to better understand factors that influence the sustainability of an evidence-based spine care program in these communities. Current
and past research and training efforts by members of the WSC research committee revealed some unique challenges requiring specific facilitators to ensure success.

This article aims to describe the selected projects within the WSC research and training programs, the challenges encountered in carrying out the research or training, and the facilitators that allowed researchers and clinicians to overcome these challenges and to complete their projects.

**WSC Research and Training Programs**

The WSC research committee was created specifically to oversee research and training projects, to ensure that scientific and ethical standards are maintained, to encourage the training of local researchers, and to monitor and correlate results from these projects. The WSC research committee meets online once a month to review new proposed projects, to discuss progress reports, and to resolve problems of ongoing projects.

Current research projects include designing a clinical database for longitudinal data collection at the WSC clinics, conducting a case series of patients seeking care at the WSC clinics, conducting qualitative studies to better understand the meaning and impact of spine and musculoskeletal ailments in underserved communities, exploring the relationship between the WSC health-care personnel and traditional healers (not described here), and developing outcome instruments in multiple languages for low-literacy and underserved populations.

Current WSC training programs provide fellowship opportunities for health-care providers in Botswana (population, 2.3 million) and for a local Motswana (a single Tswana person) orthopaedic surgeon to establish spine surgical expertise in the country, to deliver spine care conferences to inform local health-care providers and to encourage evidence-based spine care, and to train yoga instructors, physical therapists, and chiropractors drawn from the local communities (the latter two projects are not discussed in this article).

The sustainability of spine programs in low and middle-income countries requires working with local governments, evaluating community needs, mutually collaborating to create a continuum of patient care, and educating local health-care providers to assume responsibility for the clinical site(s). The long-term vision of the WSC is consistent with the priorities established by the WHO in its Framework on integrated people-centred health services, which encourages countries to reform health service delivery to support equitable access to evidence-based and patient-focused health services coordinated within and across health systems while actively engaging local communities in its development. The WSC has recently received recognition for its work in this area by the WHO as an integrated practice example for spine health (http://www.integratedcare4people.org/practices/315/creating-a-sustainable-model-of-spine-care-in-underserved-communities-in-botswana/).

Descriptions follow of the 4 projects, including the project aims, challenges encountered, facilitators, and successes achieved for each.

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**Project 1: Establishing Spine Surgery Expertise in Botswana, a Training and Implementation Project**

Spinal surgery is one of the major domains of spine care in which expertise is scarce in underserved areas. The few overworked neurosurgeons or orthopaedic surgeons practicing in low and middle-income countries, where the level of proficiency of support staff and surgical resources are limited, struggle to provide solutions for people with serious spinal disorders and trauma. With the shortage of trained spine surgeons in sub-Saharan Africa, many surgeons find themselves forced to compromise the standard of care simply to get through the sheer volume of surgical cases. Furthermore, there is a much higher prevalence of serious spinal abnormality such as tuberculosis and trauma in low and middle-income countries.

Not only is there a lack of trained support staff and nursing personnel, but surgical spine procedures are costly in terms of implants and instrument sets, most of which are unaffordable in parts of Africa. The aim of this project was to explore the opportunities for advanced spine surgery training for orthopaedic surgeons and neurosurgeons from sub-Saharan Africa and to describe the challenges associated with establishing a spine surgical program in Botswana.

Obstacles that a surgeon faces when considering advanced spine surgical training include finding a program that accepts fellows from the region where they reside, obtaining funding necessary to complete the program, and working in a foreign-language environment. Once enrolled, the trainee may find it difficult to not only adapt to a different culture, but also cope with the demands of a high-profile academic environment.

To our knowledge, because there are few spine surgeons in sub-Saharan Africa and, outside of limited opportunities in South Africa, formal spine-training programs on the continent do not exist, the WSC looked abroad (Asia, Australia, Europe, and North America) for programs that would accept fellows from Botswana. These training programs are often extremely competitive, as trainees from low and middle-income countries must compete with trainees from the host country. The WSC was fortunate to identify a Motswana surgeon with an interest in advanced training in spine surgery and a mentor. A senior spine surgeon who participates in the WSC programs agreed to mentor the Motswana surgeon during a fellowship at the Ankara ARTES Spine Center in Ankara, Turkey (Fig. 2). Funding was provided by the government of Botswana and a medical technology company (Table I).

What became obvious from this project is that, in the long term, sub-Saharan African countries will need to train the next generation of spine surgeons. For that to happen, mentors in the developed world need to be encouraged to accept and to fund spine surgical fellows. In addition, an essential requirement to attain adequate surgical services in communities with limited resources is to encourage spine device companies to provide implants and other instrumentation at a much-subsidized price.

Training fellowships inevitably develop into long-lasting collaborative relationships between mentor and mentee and their respective institutions and countries. This collaboration has the potential of lasting decades, resulting in further exchanges.
of ideas, education, and participation in multicultural clinical and research programs. The 1-year spine fellowship was completed in May 2016, and the spine surgeon returned to Gaborone, Botswana, to open the first spine center in the public health-care system funded by the Botswana Ministry of Health.

Project 2: A Case Series of Patients with Musculoskeletal Conditions Presenting to a WSC Clinic in Moca, Dominican Republic

This study was conducted from October to December 2015 in Moca, Dominican Republic (population, about 173,000), with the goal of following patients presenting to the WSC clinic in an area in which no other spine clinic exists. The case series was designed to describe patient characteristics and how musculoskeletal and spine pain impacts patients’ functional abilities and quality of life.

One of the first challenges faced in conducting research on patients in a low or middle-income country is navigating the ethics review board in the host country. In this case, the process relied upon an intermediary representative from the Dominican Republic who communicated with the Ministry of Health on behalf of the research team. Although approval was received on the first effort, the process was quite lengthy and no clear timelines for the process were stipulated. To aid future researchers, individuals should ensure that an appropriate amount of time (6 to 9 months) is allocated to guarantee ethics approval from the host country.

A second challenge that soon became evident was the timing of the project. Patient data collection with a foreign graduate student on a fixed timeline requires sufficient patient flow for patient recruitment. The current study occurred before the holiday season when, in many countries, clinics note a decrease in patient flow and staff take vacations. Researcher travel schedules, funding, and clinical data collection time-frames posed a challenge and substantially impacted the number of patients who could participate. To optimize patient recruitment and data collection in future studies, improved communication between researchers and clinical volunteers at the clinics is recommended. To aid future researchers, it is important to ensure that data collection dates do not coincide with scheduled clinic holiday closures or clinic supervisor administrative responsibilities (e.g., database and patient record maintenance) in the host country.

Two additional challenges that affected this type of research included a marked cultural difference in patient attitudes and practicalities toward structured appointment times and clinical research paperwork. First, the relaxed attitude toward schedules often had patients missing appointments or arriving at unscheduled times, which is related to the complexities of daily life including limited transportation resources. Second, patients who had never before encountered a clinical study were not accustomed to the volume of paperwork necessary to satisfy research protocol requirements. This typically resulted in patients becoming fatigued with paperwork and requiring assistance to complete questionnaires. To address this challenge, a dedicated clinical assistant was needed to guide the patient through the paperwork while the researcher verified accuracy. A lesson learned from these observations is that, in future studies of this type, researchers should streamline paperwork as much as
possible and should be cognizant of the burden that extensive paperwork places on clinical support staff and patients.

A large facilitating factor for study success was that, although paperwork was labor-intensive for patients, clinical staff, and researchers, all invited individuals willingly participated, resulting in a 0% refusal rate. It was helpful that the research investigator spoke the native language.

This study allowed the researcher to describe, identify, and establish baseline information on the population of patients receiving care at the WSC Moca clinic in the Dominican Republic. The knowledge and information gained from this study, with confidence, will result in an improvement to clinical protocols and procedures. In addition, this study explored the association of prognostic factors with patient-reported outcomes and may generate hypotheses for future studies. The study was successfully completed and was approved as a residency thesis at the Canadian Memorial Chiropractic College in Toronto. The study costs are presented in Table I.

**Project 3: The Development of Culturally Relevant Patient-Reported Outcome Measures for Low-Literacy Populations**

To systematically collect outcomes in the WSC clinics in various regions of the world, the clinical and research teams initially used validated patient-reported outcome measures. However, it became clear that these instruments, developed for literate populations in high-income countries, were not performing as expected in low-literacy populations in low and middle-income country settings. Major challenges with validated patient-reported outcome measures from industrialized countries tested in a low-income, low-literacy, rural district in Botswana included lack of understanding of numerical scales, uninformed patients and clinical staff with no numeric scale on the form, and inappropriate terms such as pain and functional rating scales, times, distances, and concepts such as averages; lack of understanding of terms such as depression and anxiety; certain activities of daily living being not applicable to the population (i.e., driving, climbing stairs, vacuuming); and cultural differences in how pain and disability are perceived and are interpreted.

A systematic literature search conducted in 2015 did not reveal validated, spine-focused, patient-reported outcome measures for use in low-literacy populations. The WSC research committee created and tested a novel patient outcomes questionnaire adapted for low-literacy populations: the clinic follow-up questionnaire. The clinical follow-up questionnaire included the following domains, each of which revealed validated, spine-focused, patient-reported outcome measures.

### TABLE I Funders, Funding Amount, and Volunteer Contribution for Research and Training Projects*

<table>
<thead>
<tr>
<th>Project</th>
<th>Funder(s)</th>
<th>Funding Purpose†</th>
<th>Amount‡</th>
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<tbody>
<tr>
<td>Establishing spine surgery expertise in Botswana, a training and implementation project§</td>
<td>Botswana Ministry of Health and Medtronic EMEA (Europe, Middle East, Africa)</td>
<td>Continuing medical education or surgical workshops, general living expenses, health insurance and registration, housing, surgical equipment, and travel expenses</td>
<td>$39,000</td>
</tr>
<tr>
<td>A case series of patients with musculoskeletal conditions presenting to a WSC clinic in Moca, Dominican Republic#</td>
<td>Canadian Memorial Chiropractic College</td>
<td>Clinic or research assistant, documentation notarization, housing, research supplies, and travel expenses</td>
<td>$2,450</td>
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<tr>
<td>The development of culturally relevant patient-reported outcome measures for low-literacy populations **</td>
<td>Botswana Ministry of Health and the WSC</td>
<td>Clinic supervisor stipend, clinic or research assistant, clinical offices, housing and utilities, volunteer travel expenses, WSC research committee volunteered time (in-kind contribution), WSC volunteer assistance (in-kind contribution), and WSC volunteer statistician (in-kind contribution)</td>
<td>$55,600</td>
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<tr>
<td>Burden of musculoskeletal disorders among villagers in rural Botswana: a focused ethnography</td>
<td>Danish Foundation for Chiropractic Research &amp; Postgraduate Education, National Chiropractic Mutual Insurance Company (NCMII) Foundation, University of Southern Denmark Faculty of Health Sciences, and the WSC</td>
<td>Manuscript preparation and submission, project expenses (translators, interpreters, transcriptionists, transcription foot pedals, photocopies, color brochures; shipping costs; extension permit to stay in Botswana), and travel expenses during 3 trips to Botswana</td>
<td>$72,000</td>
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*The detailed funding amounts are available from the corresponding author upon request. †These amounts are approximate and are reported in United States dollars. §The funding was over a 1-year period. #The project funding was over a 2-month period. **This is the estimated cost for the development of patient-reported outcome measures; the project is ongoing.
COPCORD (Community Oriented Program for Control of Rheumatic Diseases)\(^{17}\); and a brief, two-item depression assessment\(^{18}\).

The clinical follow-up questionnaire was pilot-tested on 57 consecutive patients in two WSC clinics in Shoshong and Mahalapye, Botswana. Patients received the clinical follow-up questionnaire after their first 8 treatments or until they were discharged from care, whichever came first. Patients had little difficulty understanding the questions and selecting responses in the clinical follow-up questionnaire. Feasibility study results indicated that the clinical follow-up questionnaire was responsive to changes in symptoms and physical function. The most difficult question for patients was the Wong-Baker faces to rate their pain, indicating that additional revisions are needed (Fig. 3).

In addition, we developed an adverse effects questionnaire to capture the bothersomeness and duration of the most common side effects from interventions. The questionnaire queried patients about tiredness, stiffness or tightness in the muscles or joints, increased pain, soreness, nausea, headache, dizziness, and bruising. For each adverse effect, symptoms were rated on a 3-point scale as not very bothersome, bothersome, or very bothersome. The duration of adverse effects was captured as <1 day, between 1 and 3 days, or >3 days.

This project was sponsored by the WSC research committee with researchers and clinicians volunteering their time to develop the questionnaire. A poster was presented at the International Society for the Study of the Lumbar Spine (ISSLS) SpineWeek in May 2016 in Singapore\(^{19}\). In the long term, funding is needed to establish and maintain a secure relational database for longitudinal research as well as, ideally, a dedicated database manager to manage data from the WSC clinics established in multiple countries.

**Project 4: Burden of Musculoskeletal Disorders Among Villagers in Rural Botswana: A Focused Ethnography**

This qualitative project examined the burden of living with musculoskeletal conditions in rural Botswana. Fieldwork included 3 visits spanning 8 months in the country and allowed us to develop useful methods\(^{20}\) to conduct the work in two languages. Study findings\(^{21,22}\) are expected to inform the WSC efforts to establish clinics, programs, and research in multiple countries where volunteers do not speak the local language(s). Notwithstanding language barriers, international researchers will likely face two challenges at WSC sites: timelines and local collaborations. Overcoming both challenges requires sufficient funding to sustain research efforts.

The timing to obtain research approval from Ministries of Health may not coincide with academic timelines in high-income countries. Digital divides between countries hamper efforts to obtain a clear understanding of research review cycles, approval processes, and current administrator details. Web sites for ethics review were outdated and online submissions were not possible. E-mail communications were often unanswered. Persistent, ongoing follow-up was required. Although direct telephone contact was sometimes helpful, in-person meetings were vital to facilitate research efforts and to obtain official permits. This required funded personnel to spend time in the country to build relationships with government officials and local citizens that may not be anticipated by researchers. Project timelines and budgets must be adjusted for successful implementation. However, 3 trips to Botswana over 3 years, funded by several sources, did allow us to establish reasonable timelines for this multinational collaborative effort.

The second challenge to generating meaningful information is local collaboration. Researchers must engage local investigators and research personnel before, during, and after...
data collection. Verbatim interview transcription lagged during fieldwork because of an underdeveloped research infrastructure. Collaboration in which we cultivated relationships and trust with villagers and village ward chiefs helped to remedy this challenge. Of value, this project contributed to the local economy by hiring, training, and retaining a small cadre of villagers to develop research skills and to participate in data collection. Future efforts require sufficient funding for local investigators to devote protected time to collaborate before, during, and after fieldwork, the prospects of which are exciting. This project was successfully defended as a doctoral (PhD) thesis in December 2015 at the University of Southern Denmark in Odense and generated a number of publications.

**Synthesis of Challenges and Facilitators**

Table II summarizes project challenges and facilitators. The rewards greatly surpass the challenges as identified collectively by project investigators. All projects were accomplished, albeit not always as planned and with some changes along the way, but this is expected when implementing novel research and training efforts. One of the WSC’s goals is to build a community of researchers for low and middle-income countries where

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<tr>
<th>Domain</th>
<th>Challenges</th>
<th>Facilitators</th>
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<tr>
<td>Establishing spine surgery expertise</td>
<td>Language(s) for non-citizens of host country</td>
<td>Local citizens who volunteer or are selected for training</td>
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<td></td>
<td>Shortage of mentors and training programs in country for spine surgeons</td>
<td>Volunteer mentors from abroad with established training programs and funding</td>
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<td></td>
<td>Lack of resources for surgical spine procedures (i.e., blood, implants, instrument sets)</td>
<td>Corporate sponsors, government and nongovernmental organization (NGO) resources devoted to spine surgery</td>
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<td></td>
<td>Limited academic environments for trainee</td>
<td>Collaborative program built on mutual respect</td>
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<td></td>
<td>Recognition of spine surgical expertise</td>
<td>Evidence-based training programs in country</td>
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<td>Data collection at WSC clinics</td>
<td>Navigating ethics review process in developing country</td>
<td>Persistence and sufficient time (6 to 9 months) to obtain approvals, academic institutional support from internal review board, local investigators, or clinicians trained in research to facilitate timely ethical review process</td>
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<td></td>
<td>WSC clinic closures for holidays or administrative activities</td>
<td>Clear communication between WSC clinical, administrative, and research teams</td>
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<td></td>
<td>Cultural differences for scheduling patient clinic visits</td>
<td>Flexibility of WSC clinic processes to adapt to local customs</td>
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<tr>
<td></td>
<td>Patient and clinic personnel burden for data collection to conduct research</td>
<td>Funding for dedicated research personnel to facilitate data collection and follow-up and to manage data repository</td>
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<td></td>
<td>Low literacy for data collection instruments typically designed as self-report measures</td>
<td>Qualitative research methods to develop appropriate outcome measures</td>
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<tr>
<td>Data collection in communities served by WSC clinics</td>
<td>Language(s) for non-citizens of host country</td>
<td>Learn local language(s)</td>
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<tr>
<td></td>
<td>Timelines in academia may not coincide with project timelines in country</td>
<td>Build local research capacity; hire, train, and retain local translators, interpreters, and transcriptionists</td>
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<td></td>
<td>Minimal established relationships with government staff, village authorities, elders, and villagers</td>
<td>Sufficient funding for time in country to cultivate relationships, conduct research, and disseminate findings</td>
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<tr>
<td></td>
<td>Minimal established collaborative relationships with host country investigators</td>
<td>Funding and protected time for host country investigators to engage in research activities</td>
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there is limited understanding of spinal disorders and a lack of evidence-based spine care and to begin the process of supporting host countries and foreign charities, institutions, and organizations interested in collaborative projects.

Anyone interested in pursuing projects must have a clear study design, protocol, methods, adequate funding, and approval from local authorities. In addition, when conducting research or training in low and middle-income countries, the logistics and research protocols widely accepted in high-income countries may not automatically apply in low and middle-income countries. It is crucial for such projects to adapt to local customs and be flexible for modifications to different languages and cultures.

In conclusion, research endeavors can have a major impact on spine care programs by the WSC and other organizations. To date, the lessons learned include the importance of incorporating stakeholder perspectives, understanding knowledge transfer activities in other cultures, and ensuring optimal organizational and mutual collaborative relationships among researchers, clinicians, local governments, and local community leaders. With cooperation and funding, it is possible to conduct the research necessary to provide sustainable spine care programs that have the potential to improve the public’s health and quality of life.

References


