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Prosthetic and Orthotic Services in Developing Countries

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Abstract

Aim: The overall aim of this thesis was to generate further knowledge about prosthetic and orthotic services in developing countries. In particular, the thesis focused on patient mobility and satisfaction with prosthetic and orthotic devices, satisfaction with service delivery, and the views of staff regarding clinical practice and education. **Methods:** Questionnaires, including QUEST 2.0, were used to collect self-reported data from 83 patients in Malawi and 139 patients in Sierra Leone. In addition, 15 prosthetic/orthotic technicians in Sierra Leone and 15 prosthetists/orthotists in Pakistan were interviewed. **Results:** The majority of patients used their prosthetic or orthotic devices (90% in Malawi, and 86% in Sierra Leone), but half of the assistive devices in use needed repair. Approximately one third of patients reported pain when using their assistive device (40% in Malawi and 34% in Sierra Leone). Patients had difficulties, or could not walk at all, with their prosthetic and/or orthotic device in the following situations; uneven ground (41% in Malawi and 65% in Sierra Leone), up and down hills (78% in Malawi and 75% in Sierra Leone), on stairs (60% in Malawi and 66% in Sierra Leone). Patients were quite satisfied or very satisfied with their assistive device (mean 3.9 in Malawi and 3.7 in Sierra Leone out of 5) and the services provided (mean 4.4 in Malawi and 3.7 in Sierra Leone out of 5), ($p < 0.001$), but reported many problems (418 comments made in Malawi and 886 in Sierra Leone). About half of the patients did not, or sometimes did not, have the ability to access services (71% in Malawi and 40% in Sierra Leone). In relation to mobility and service delivery, orthotic patients and patients using above-knee assistive devices in Malawi and Sierra Leone had the poorest results. In Sierra Leone, women had poorer results than men. The general condition of devices and the ability to walk on uneven ground and on stairs were associated with both satisfaction of assistive devices and service received. Professionals' views of service delivery and related education resulted in four themes common to Sierra Leone and Pakistan: 1) Low awareness and prioritising of prosthetic and orthotic services; 2) Difficulty managing specific pathological conditions and problems with materials; 3) The need for further education and desire for professional development; 4) Desire for improvements in

prosthetic and orthotic education. A further two themes were unique to Sierra Leone; 1) People with disabilities have low social status; 2) Limited access to prosthetic and orthotic services. **Conclusion:** High levels of satisfaction and mobility while using assistive devices were reported in Malawi and Sierra Leone, although patients experienced pain and difficulties when walking on challenging surfaces. Limitations to the effectiveness of assistive devices, poor comfort, and limited access to follow-up services and repairs were issues that needed to be addressed. Educating prosthetic and orthotic staff to a higher level was considered necessary in Sierra Leone. In Pakistan, prosthetic and orthotic education could be improved by modifying programme content, improving teachers' knowledge, improving access to information, and addressing issues of gender equality.

Key words: assistive device, Convention of Rights of Persons with Disabilities, disability, low-income countries, mobility, orthosis, prosthesis, satisfaction, QUEST.

Abstract in Arabic

خدمات الأطراف الاصطناعية وتقويم العظام في البلدان النامية

الهدف: الهدف العام من هذه الرسالة توليد مزيد من المعرفة حول خدمات الأطراف الاصطناعية وتقويم العظام في البلدان النامية. على وجه الخصوص، ركزت الأطروحة على حرية الحركة و التنقل للمرضى والرضا عن الأجهزة التعويضية وتقويم العظام، و علا الرضا عن تقديم الخدمات وآراء الموظفين بشأن الممارسة السريرية والتعليم. الأدوات والطرق : استخدمت استبيانات بما في ذلك QUEST 2.0 لجمع البيانات المبلغ عنها ذاتيا من ٨٣ مرضى في ملاوي و ١٣٩ مريضا في سيراليون. بالإضافة إلى ذلك، أجريت مقابلات مع ١٥ من فنيين تقويم العظام و الأطراف الاصطناعية في باكستان و ١٥ اخرون في سيراليون . النتائج: غالبية المرضى استخدموا اجهزتهم الاصطناعية المساعدة أو أجهزة تقويم العظام (٩٠٪ في ملاوي، و ٨٦٪ في سيراليون)، ولكن نصف هذه الأجهزة المساعدة المستخدمة في حاجة لإصلاح وترميم . حوالي ثلث المرضى ابلغوا عن الشعور بالألم عند استخدام أجهزتهم المساعدة (٤٠٪ في ملاوي و ٣٤٪ في سيراليون). وعانى المرضى من الصعوبات، أو لم يستطيعوا المشي بناتا علي أرض غير ممهده (٤١٪ في ملاوي و ٦٥٪ في سيراليون)، صعودا ونزولا من التلال (٧٨٪ في ملاوي و ٧٥٪ في سيراليون) وعلى الدرج (٦٠٪ في ملاوي و ٦٦٪ في سيراليون). المرضى كانوا راضين تماما أو راضون جدا عن أجهزتهم المساعدة (متوسط ٣,٩ في ملاوي و ٣,٧ في سيراليون من مقياس ٥ درجات) وعن الخدمات المقدمة (متوسط ٤,٤ في ملاوي و ٣,٧ في سيراليون من مقياس ٥)، قيمه ص اقل من واحد من الالف ($p > 0.001$)، ولكن ذكرت العديد من المشاكل (١٨٨ من التعليقات الواردة في ملاوي و ٨٨٦ منها في سيراليون). حوالي نصف المرضى لم تستطع، أو في بعض الأحيان لم يكن لديهم إمكانية الوصول إلى الخدمات (٦٧٪ في ملاوي و ٤٠٪ في سيراليون). فيما يتعلق بالتنقل وتقديم الخدمات، اظهر المرضى ذوي أجهزة المساعدة لتقويم العظام فوق الركبة في الملاوي وسيراليون ادني النتائج، في سيراليون كانت النتائج اكثر تدينيا للنساء من الرجال. ارتبطت الحالة العامة للأجهزة المساعدة والقدرة على المشي على أرض غير مستوية مع كل من الرضا عن الاجهزه المساعدة والخدمات المستلمة. أسفرت آراء المهنيين لتقديم الخدمات والتعليم ذات الصلة عن أربعة محاور مشتركة لسيراليون وباكستان: (١) انخفاض الوعي وتحديد الأولويات من خدمات الأطراف الاصطناعية وتقويم العظام. (٢) صعوبة التعامل مع حالات مرضية معينة وصعوبات فنيه مع المواد، (٣) الحاجة إلى مزيد من التعليم والرغبة في التطوير المهني و(٤) الرغبة في إدخال تحسينات في مجال التعليم للأطراف الاصطناعية وتقويم العظام. علاوة على ذلك ظهرت محاور متفرده لسيراليون: (١) الأشخاص ذوي الإعاقة كانوا من اصحاب والوضع المتدني. (٢) محدودية الوصول إلى خدمات الأطراف الاصطناعية وتقويم العظام. الاستنتاج: تم الإبلاغ عن مستويات عالية من الرضا وحرية الحركة و التنقل أثناء استخدام الأجهزة المساعدة في الملاوي وسيراليون على الرغم من شعور المرضى بالألم وصعوبه المشي على الأسطح الصعبة. القيود في فعالية الاجهزة المساعدة، وقله الراحة ومحدودية الوصول إلى الخدمات والإصلاحات ومتابعة القضايا التي تحتاج إلى معالجة. تثقيف الموظفين الاصطناعية وتقويم العظام إلى مستوى أعلى من الضرورة في

سيراليون. بينما في باكستان، يمكن تحسين اتعليم الاطراف الاصطناعية وتقويم العظام عن طريق تعديل محتوى البرنامج، ورفع مستوى معرفة المعلمين، وتحسين الوصول إلى المعلومات ومعالجة قضايا المساواة بين الجنسين.

الكلمات الرئيسية: جهاز المساعدة، واتفاقية حقوق الأشخاص ذوي الإعاقة والعجز، البلدان ذات الدخل المنخفض، التثقيف، والأجهزة والتقويمية الاطراف الاصطناعية، رضائهم (QUEST).

Abstract in Chinese

发展中国家的义肢矫形服务

目标：本论文的总体目标是进一步了解发展中国家的义肢矫形服务。

本论文重点研究使用义肢矫形器的患者的运动情况，对义肢矫形器和义肢矫形服务的满意度及义肢矫形的修配人员对于临床工作和相关教育的看法。**方法：**问卷QUEST2.0

用于收集83名马拉维患者和139名塞拉利昂患者的自我报告数据。15名塞拉利昂的义肢矫形的修配人员和15名巴基斯坦的义肢矫形的修配人员接受访谈。**结果：**绝大多数的患者使用过义肢或矫形器（90%的马拉维患者和86%的塞拉利昂患者），但是其中50%在使用中的辅助器需要维修。将近1/3的患者主诉在使用辅助器的时候会出现疼痛（40%的马拉维患者和34%的塞拉利昂患者）。41%的马拉维患者和65%的塞拉利昂患者在使用义肢矫形器行走于不平坦的地面的时候表示困难或完全无法行走；78%的马拉维患者和75%的塞拉利昂患者使用义肢矫形器上下斜坡时存在困难或完全无法行走；60%的马拉维患者和66%的塞拉利昂患者使用义肢矫形器上楼时存在困难或完全无法行走。虽然患者指出了很多问题（马拉维患者提出418条建议，塞拉利昂患者提出了886条建议），但患者对于他们的义肢矫形器（马拉维均值为3.9，塞拉利昂均值为3.7，满分为5）和义肢矫形服务（马拉维均值为4.4，塞拉利昂均值为3.7，满分为5）表现的非常满意。大约一半的患者不能或者有时不能获得义肢矫形服务（71%的马拉维患者和40%的塞拉利昂患者）。对于行动能力和义肢矫形服务，使用矫形器的患者和使用膝盖以上辅助器的患者表现了最坏的调查结果。在塞拉利昂，女性的调查结果要差于男性。辅助器的情况和在不平坦地面行走的能力与患者对辅助器和义肢矫形服务的满意度相关。对于马拉维和塞拉利昂的义肢矫形服务和相关教育，专家们的观点主要是以下四个方面：1) 对于义肢矫形服务的认识和优先排序较差；2) 难以管理由于义肢矫形器材料所引起的特定的病理性情况和问题；3) 更进一步教育的需求和专业发展的渴望；4) 渴望改进义肢和矫形器使用的健康教育。除此之外，塞拉利

昂仍存在两个特别的方面：1) 残疾人的地位较低；2) 接受义肢矫形服务受限。**总结**：在马维拉和塞拉利昂，患者们虽然经历着行走带来的疼痛和困难，但是他们仍对义肢矫形器的使用和行动能力表现了高水平的满意度。辅助器使用的有限效果，较差的舒适度，有限的跟踪服务和义肢矫形器的维修问题都需要处理。塞拉利昂还需要进一步的教育培养义肢矫形器的修配人员使其达到较高的专业水平。在巴基斯坦，通过修改项目内容，增加教师的知识，提高信息的获取和解决性别平等问题可以促进义肢矫形教育的发展。

关键词：辅助器、残疾人权利公约、残疾、低收入国家、行动、矫形器、义肢、满意度、QUEST

Abstract in French

Services d'orthèses et prothèses dans les pays en développement

Objectif: L'objectif général de cette thèse est de générer de nouvelles connaissances sur les services d'orthèses et prothèses dans les pays en développement. En particulier, la thèse a porté sur la mobilité et la satisfaction des patients avec leurs prothèses et orthèses, la satisfaction sur la prestation de services et sur le point de vue du personnel concernant la pratique clinique et de l'éducation. **Méthodes:** Des questionnaires dont le QUEST 2.0 ont été utilisés pour recueillir des données auto déclarées de 83 patients au Malawi et 139 patients en Sierra Leone. En outre, 15 techniciens orthoprothésistes en Sierra Leone et 15 orthoprothésistes au Pakistan ont été interrogés. **Résultats:** La majorité des patients ont utilisé leurs prothèses ou orthèses (90% au Malawi et 86% en Sierra Leone), mais la moitié des aides techniques en usage nécessitaient des réparations. Environ un tiers des patients ont signalé une douleur lors de l'utilisation de leur appareil (40% au Malawi et 34% en Sierra Leone). Les patients ont eu des difficultés, ou ne pouvaient pas marcher du tout, sur; sol inégal (41% au Malawi et 65% en Sierra Leone), et lors de descente (78% au Malawi et 75% en Sierra Leone) et dans les escaliers (60% au Malawi et 66% en Sierra Leone). Les patients étaient satisfaits ou très satisfaits de leur appareil (moyenne de 3,9 au Malawi et en Sierra Leone 3,7 sur 5) et des services fournis (moyenne de 4,4 au Malawi et en Sierra Leone 3,7 sur 5), ($p < 0,001$), mais ont signalé de nombreux problèmes (418 commentaires faits au Malawi et 886 en Sierra Leone). Environ la moitié des patients n'ont pas, ou parfois ne pas la possibilité d'accéder à des services (71% au Malawi et 40% en Sierra Leone). En ce qui concerne la mobilité et la prestation de services, les patients utilisant des orthèses et des prothèses trans-fémorales au Malawi et en Sierra Leone, ont eu les résultats les plus faibles. En Sierra Leone, les femmes ont de moins bons résultats que les hommes. L'état général des appareils et la capacité de marcher sur un terrain accidenté ont été associés à la satisfaction des appareils et des services reçus. Les points de vue des professionnels sur la prestation des services et l'éducation a permis de faire

ressortir quatre thèmes communs à la Sierra Leone et le Pakistan; 1) Le manque de sensibilisation sur les services d'appareillage ainsi que leur bas niveau dans la hiérarchisation des priorités; 2) Difficulté de prendre en charge des conditions et des problèmes spécifiques avec les matériaux disponible, 3) Nécessité de poursuivre la formation et la volonté de développement professionnel et 4) Désir d'amélioration de la formation en prothèses et d'orthèses. Deux autres thèmes étaient uniques pour la Sierra Leone; 1) Les personnes handicapées ont un faible statut et 2) L'accès limité aux services de prothèse et d'orthèse. **Conclusion:** Des niveaux élevés de satisfaction et de mobilité lors de l'utilisation d'aides techniques ont été rapportés au Malawi et en Sierra Leone, bien que les patients aient présentés des douleurs et des difficultés à marcher sur des surfaces difficiles. Les limitations de l'efficacité des appareils, le manque de confort et l'accès limité aux services de suivi et les réparations sont des points qui doivent être pris en compte. Le besoin de formation, a un niveau supérieur, du personnel en prothèses et d'orthèses est nécessaire en Sierra. Au Pakistan, la formation en prothèses et d'orthèses pourrait être améliorée en modifiant le contenu du programme, en augmentant le niveau des connaissances des enseignants, en améliorant l'accès à l'information et en prenant en compte les questions d'égalité des sexes.

Mots clés: aide technique, Convention Relative aux Droits des Personnes Handicapées, handicap, pays à faible revenu, mobilité, orthèse prothèse, satisfaction, QUEST.

Abstract in Russian

Протезирование и Ортопедические услуги в развивающихся странах

Цель: Общей целью данной диссертации было получение дополнительных данных об услугах по протезированию и ортопедии, предоставляемых в развивающихся странах. В частности, диссертация посвящена вопросам подвижности пациентов и их удовлетворенности протезами и ортопедическими устройствами, удовлетворенности предоставлением услуг, а также мнению персонала, занятого в данной отрасли, по поводу клинической практики и образования. **Методы:** с целью сбора данных, предоставляемых пациентами, были использованы анкеты, в том числе QUEST 2.0; таким образом, были получены данные для 83-х пациентов в Малави и 139-ти пациентов в Сьерра-Леоне. В дополнение к этому, был проведен опрос среди 15-ти специалистов в сфере протезирования/ортопедии в Сьерра-Леоне и 15-ти аналогичных специалистов в Пакистане. **Результаты:** Большинство пациентов пользуется своими протезами или ортопедическими устройствами (90% в Малави и 86% в Сьерра-Леоне), но половина используемых вспомогательных устройств нуждается в ремонте. Примерно треть пациентов сообщали о болезненных ощущениях при использовании вспомогательного устройства (40% в Малави и 34% в Сьерра-Леоне). Пациенты сталкивались с трудностями или вообще не могли передвигаться при помощи своего протеза или ортопедического устройства по: неровной поверхности (41% в Малави и 65% в Сьерра-Леоне), вверх и вниз по холмам (78% в Малави и 75% в Сьерра-Леоне) и по ступенькам (60% в Малави и 66% в Сьерра-Леоне). Пациенты были в достаточной степени удовлетворены или полностью удовлетворены своими вспомогательными устройствами (средний балл 3,9 в Малави и 3,7 в Сьерра-Леоне в целом из 5-ти) и предоставляемыми услугами (средний балл 4,4 в Малави и 3,7 в Сьерра-Леоне в целом из 5-ти), ($p < 0,001$), но сообщали о многочисленных проблемах (было оставлено 418 замечаний в Малави и 886 в Сьерра-Леоне). Примерно половина пациентов вообще или в некоторых случаях не имела доступа к услугам (71% в Малави и 40% в Сьерра-Леоне). Что касается мобильности и предоставления услуг, наихудшие результаты были отмечены среди пациентов, использующих ортопедические устройства и вышеуказанные вспомогательные устройства (протезы) для коленных суставов в Малави и Сьерра-Леоне. В Сьерра-Леоне результаты у женщин были хуже, чем у мужчин. Удовлетворенность вспомогательными устройствами и предоставленными услугами определялась общим состоянием устройств и

возможностью ходьбы по неровным поверхностям. Опрос мнений профессионалов по поводу предоставления услуг и соответствующего обучения позволил выделить четыре аспекта, общих для Сьерра-Леоне и Пакистана: 1) низкая степень осведомленности населения и определения приоритетов в сфере услуг протезирования и ортопедических услуг; 2) сложности при лечении определенных патологических состояний и проблемы с материалами, 3) потребность в дополнительном образовании и стремление к профессиональному росту и 4) Стремление к усовершенствованию образования в сфере протезирования и ортопедии. Еще две дополнительных проблемы были характерными только для Сьерра-Леоне: 1) лица с ограниченными физическими возможностями обладают низким социальным статусом и 2) ограниченный доступ к услугам протезирования и ортопедическим услугам. **Вывод:** В Малави и Сьерра-Леоне были зафиксированы высокий уровень удовлетворенности и мобильности пациентов при использовании ими вспомогательных устройств, хотя у пациентов наблюдались болезненные ощущения и трудности при ходьбе по сложным для преодоления поверхностям. Проблемы, требующие решения, включали ограниченную эффективность вспомогательных устройств, низкий уровень комфорта и ограниченный доступ к таким услугам, как последующее обслуживание и ремонт устройств. В Сьерра-Леоне была выявлена потребность в более высоком уровне обучения специалистов в сфере протезирования и ортопедии. В Пакистане соответствующее обучение может быть усовершенствовано путем модификации содержания программы обучения, повышения уровня знаний преподавательского состава, облегчения доступа к информации и решения проблемы равенства полов.

Ключевые слова: вспомогательное устройство, Конвенция о правах инвалидов, инвалидность, страны с низким уровнем доходов, мобильность, ортопедический аппарат, протез, удовлетворенность, анкета QUEST.

Abstract in Spanish

Servicios de Prótesis y Órtesis en los Países en Desarrollo

Objetivo: El objetivo general de esta tesis fue generar un mayor conocimiento acerca de los servicios de prótesis y órtesis en los países en desarrollo. En particular, la tesis se centró en la movilidad y la satisfacción del paciente con las ayudas ortopédicas protésicas y órtesicas, la satisfacción con la prestación de servicios y las opiniones del personal con respecto a la práctica clínica y la educación. **Métodos:** Los cuestionarios incluidos el QUEST 2,0 se utilizaron para recoger los datos de auto-reporte de 83 pacientes en Malawi y 139 pacientes en Sierra Leona. Además, se entrevistó a 15 técnicos de prótesis/órtesis en Sierra Leona y 15 protesistas / ortesistas en Pakistán. **Resultados:** La mayoría de los pacientes utilizan sus ayudas ortopédicas protésicas y órtesicas (90% en Malawi, y el 86% en Sierra Leona), pero la mitad de las ayudas técnicas en uso requieren una reparación. Aproximadamente un tercio de los pacientes reportaron dolor al usar su ayuda ortopédica (40% en Malawi y el 34% en Sierra Leona). Los pacientes tenían dificultades, o no podían caminar en absoluto con prótesis o órtesis en; terreno irregular (41% en Malawi y el 65% en Sierra Leona), subir o bajar cerros (78% en Malawi y el 75% en Sierra Leona) y en las escaleras (60% en Malawi y el 66% en Sierra Leona). Los pacientes estaban muy satisfechos con sus ayudas ortopédicas protésicas y órtesicas (media 3,9 en Malawi y Sierra Leona 3,7 de 5) y los servicios que ofrecen (media 4,4 en Malawi y Sierra Leona 3,7 de 5), ($p < 0,001$), pero informaron muchos problemas (418 comentarios realizados en Malawi y 886 en Sierra Leona). Alrededor de la mitad de los pacientes no, o, a veces no tienen la posibilidad de acceder a los servicios (71% en Malawi y el 40% en Sierra Leona). En relación con la movilidad y la prestación de servicios, los pacientes que utilizan ayudas técnicas de asistencia por encima de la rodilla en Malawi y Sierra Leona, tuvieron los peores resultados. En Sierra Leona, las mujeres tuvieron peores resultados que los hombres. El estado general de las ayudas técnicas y la capacidad de caminar en terreno irregular se asociaron con la satisfacción de las ayudas técnicas y servicios recibidos. Puntos de vista de los profesionales de la prestación de servicios y la educación relacionada

resultaron en cuatro temas comunes a Sierra Leona y Pakistán; 1) Baja conciencia y priorización de los servicios de prótesis y órtesis; 2) Dificultades para gestionar patologías específicas y problemas de materiales, 3) Necesidad de aun mas educación y deseo de desarrollo profesional y 4) Deseo de mejorar la educación de prótesis y órtesis. Además, dos temas eran únicos para Sierra Leona; 1) Las personas con discapacidad tienen un estatus bajo y 2) El acceso a los servicios de prótesis y órtesis son limitados.

Conclusión: Se registraron altos niveles de satisfacción y movilidad durante el uso de ayudas protésicas y ortésicas en Malawi y Sierra Leona, aunque los pacientes sufrieron dolor y dificultades para caminar sobre superficies difíciles. Las limitaciones en la efectividad de las ayudas protésicas y ortésicas, falta de comodidad y un acceso limitado a los servicios de seguimiento y reparaciones eran asuntos que debían ser dirigidos. Educar al personal de prótesis y órtesis a un nivel más alto era necesario en Sierra Leona. En Pakistán, la educación de prótesis y órtesis podría mejorarse modificando el contenido del programa, actualización de los conocimientos de los maestros, mejorar el acceso a la información y abordar los asuntos de igualdad de género.

Palabras clave: ayudas técnicas ortopédicas, Convención de los Derechos de las Personas con Discapacidad, discapacidad, países de bajos ingresos, movilidad, órtesis, prótesis, satisfacción, QUEST.

Original papers

The thesis is based on the following papers, which are referred to by their Roman numerals in the text:

Paper I

Magnusson L, Ahlström G, Ramstrand N, Fransson EI. Malawian Prosthetic and Orthotic Users' Mobility and Satisfaction with their Lower-Limb Assistive Device. *Journal of Rehabilitation Medicine* 2013; 45:385–391

Paper II

Magnusson L, Ramstrand N, Fransson EI, Ahlström G. Mobility and satisfaction with lower-limb prostheses and orthoses among users in Sierra Leone: a cross-sectional study. *Journal of Rehabilitation Medicine* 2014; 46:438-446

Paper III

Magnusson L, Ahlström G, Experiences of providing prosthetic and orthotic services in Sierra Leone – the local staff's perspective. *Disability and Rehabilitation* 2012; 34:2111-8

Paper IV

Magnusson L, Ramstrand N. Prosthetists/ Orthotists Educational Experience & Professional Development in Pakistan. *Disability and Rehabilitation Assistive Technology* 2009; 4(6):385-92

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Abbreviations

CIOMS	The Council for International Organizations of Medical Sciences
CRPD	Convention of Rights of Persons with Disabilities
ICF	International Classification of Functioning, Disability and Health
ICRC	The International Committee of the Red Cross
IMF	International Monetary Fund
ISPO	International Society for Prosthetics and Orthotics
MDG	Millennium Development Goals
PIPOS	Pakistan Institute of Prosthetics and Orthotics Science
PRSP	Poverty Reduction Strategy Papers
QUEST	Quebec User Evaluation of Satisfaction with Assistive Technology questionnaire
TATCOT	Tanzania Training Center for Orthopedic Technologists
WHO	World Health Organization

Definitions

The following terms are used extensively in this thesis and defined as below.

Above-knee amputation: “Amputation of the lower-limb between the hip joint and the knee joint”, trans-femoral amputation (1).

Ankle-foot orthosis: “Orthosis that encompasses the ankle joint and the whole or part of the foot” (2).

Assistive devices: Products (including devices, equipment, instruments, technology, and software) that prevent, compensate, monitor, relieve, or neutralise impairments, activity limitations, and/or participation restrictions (3). In Study I and II use of the term assistive device refers to lower-limb prosthetic and/or orthotic devices.

Below-knee amputation: “Amputation of the lower-limb between the knee joint and the ankle joint”, trans-tibial amputation (1).

Developing countries: Low income countries and middle income countries

Knee-ankle-foot orthosis: “Orthosis that encompasses the knee and ankle joints and the foot” (2).

Lower-limb prosthesis: “Prosthesis used to replace the whole or part of the lower-limb” (4).

Lower-limb orthosis: “Orthosis applied to whole or part of the lower-limb” (4).

Orthosis; orthotic device: “Externally applied device used to modify the structural and functional characteristics of the neuromuscular and skeletal systems” (4).

Orthotic/Prosthetic technician: “A Person who, having completed an approved course of training, manufactures orthoses/prostheses under the direction of an orthotist/prosthetist” (4).

Persons with disabilities: “Includes those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (5).

Prosthesis; prosthetic device: “Externally applied device used to replace wholly, or in part, an absent or deficient limb segment” (4).

Prosthetist/orthotist: “A person who, having completed an approved course of education and training, is authorised by an appropriate national authority to design, measure and fit prostheses and orthoses” (4).

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Preface

My background and journey have influenced my work, so it seems appropriate in this thesis to include a brief description of my own journey in relation to rehabilitation and research in developing countries. I grew up with an understanding that everyone has the same value as a human being, including persons with disabilities. I had a desire to work with people in low income countries, and after graduating from school at 19 years of age, I decided to move to South Africa to work as a volunteer in a non-governmental organisation. Here, I was exposed to extreme poverty for the first time. After my initial experience I also went to work in the Philippines, delivering glasses to people with visual impairments on remote islands. On my return to Sweden I studied for a Bachelor's degree in prosthetics and orthotics and, in collaboration with Mobility India, I wrote my undergraduate thesis on prosthetic and orthotic services in relation to community-based rehabilitation in India. During my time there in 2001, I attended a conference and met two prosthetic and orthotic technicians from Sierra Leone who had been sponsored to attend by Handicap International. These technicians spoke of what had happened during the civil war that was, at the time, just about to come to an end. I was touched by their stories and interested to hear more. I became acquainted with the Sierra Leonean prosthetic and orthotic technicians, and was invited to Sierra Leone. After returning to Sweden, I worked clinically as a prosthetist/orthotist for a few years as part of a team who provided physical rehabilitation medicine services. Five years later, I studied within the international health master's programme in Uppsala, Sweden, and as part of my studies I collected research data in Sierra Leone. During this time, I had the opportunity to meet many researchers working in developing countries, and studied with people from some of these nations. I also completed a master's degree in prosthetics and orthotics, and began to teach within the prosthetic and orthotic education programme in Sweden. During my time as a PhD student and in addition to collecting my own data, I have had the privilege of supervising students conducting smaller projects in a number of developing countries.

Introduction

The studies in this thesis investigate prosthetic and orthotic services from the perspectives of patients and professionals. The results are put into the context of the society in order to gain a deeper understanding of the significance of the results. The prosthetics and orthotics profession is involved in the manufacture and provision of prosthetic devices for amputees (potential prosthetic users) and persons with other physical impairments, such as weakness or deformity (potential orthotic users). Prosthetic and orthotic services are concerned with physical rehabilitation provided by medical and allied health professionals associated with a prosthetic and orthotic workshop. This includes patient assessment, prescription and manufacture of devices, fitting, training, follow-up, and repairs. It was estimated that about 0.5% of the world's population is in need of assistive devices (6); in 2013, the number of people who required such aid was estimated at 25 million in Africa and Asia (7). The majority of these people could have increased their participation within society by receiving an assistive device to facilitate mobilisation, recognised as a step in accessing basic human rights such as food, housing, education, income, healthcare, and social inclusion. Assistive technology is required to implement the Convention of Rights of Persons with Disabilities (CRPD) (5, 8), which asserts that all people with disabilities have the right to personal mobility and available and affordable assistive technology (9). Prosthetic and orthotic services are limited in developing countries and need to be scaled up, as they have the potential to improve mobility and facilitate increased inclusion in society for amputees and persons with physical impairments. Service provision is affected by policy, poverty, and attitudes within cultures. Barriers and facilitators of service delivery for prosthetic and orthotic devices in developing countries need to be identified and addressed. Furthermore, appropriate low-cost technology needs to be further developed (10). Many developing nations do not offer formal university education in the field of prosthetics/orthotics (11). This results in limited availability of prosthetic and orthotic services provided by qualified staff for persons with physical disabilities in developing countries.

Background

The countries included in this thesis will initially be introduced. A background to health, rehabilitation, disability, and perspectives on disabilities will follow. Finally a section related to prosthetic and orthotic services in developing countries will be presented.

Countries included in this thesis



Figure 1: Sierra Leone in West Africa, Malawi is located in southern Africa, and Pakistan in South Asia.

Malawi and Sierra Leone are low income countries in sub-Saharan Africa, while Pakistan is classified as a lower middle income country in South Asia. In Malawi, the majority of the population lives under the ‘absolute poverty’ line, but the population has a relatively high literacy rate (12). Sierra Leone has a history of conflict and large violations of human rights, including

murder, mass rape, amputations, abductions, and enforced marriages. These violations occurred during the country's civil war, which took place between 1991 and 2002 (13). According to the Human Development Index (12), Sierra Leone is among the ten least developed countries in the world. Pakistan is classified as a lower middle income country on the basis of a higher gross national income. However, in Pakistan, a high percentage of the population is living under the absolute poverty line, suggesting that resources are very unevenly distributed (12). In this thesis, low income and lower middle income economies are referred to as developing countries. Table 1 presents an overview of key indicators related to the countries of interest (12).

Table 1: Development indicators for Malawi, Sierra Leone and Pakistan

Country	Malawi	Sierra Leone	Pakistan
Region	Sub-Saharan Africa	Sub-Saharan Africa	South Asia
Income level	Low income	Low income	Lower middle income
Population (millions)	16	6	183
*Human Development Index rank	174	183	146
Life expectancy at birth (years)	55	46	67
**Poverty headcount ratio at national poverty line below 1.25 US\$ per day (% of population)	62	52	21
Gross National income (GNI) per capita (US\$)	715	1815	4652
Literacy rate, adult total (% of people aged years 15 and above)	75	43	55

*"The Human Development Index provides a measure of three dimensions of human development; living a long and healthy life (measured by life expectancy), being educated (measured by adult literacy and gross enrolment in education), and having a decent standard of living (measured by purchasing power parity, PPP, income)". The rankings are presented in the table, and the total number of countries included is 187 (12).

**Absolute poverty is measured by global standards as income per capita being lower than \$1.25 a day (12).

Health and disability

According to the World Health Organization (WHO) definition, “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (14). The WHO definition of health has adopted a holistic approach to health, rather than a disease-oriented one. Health and enabling should be the focus of healthcare. A holistic health approach in healthcare means a focus on individuals' vital goals, and therefore also includes health education and rehabilitation (15). The WHO definition of health has received criticism as it characterises an ideal state which is almost never reached, and is therefore not appropriate in the context of ordinary healthcare (16) and rehabilitation.

Over the years, the WHO has launched a number of strategies concerning the provision of healthcare to achieve improved health for people. The Alma Ata declaration, “Health for All”, states that health depends on having access to medical services and means for payment for services, but also an understanding of the links between social factors and the environment (17). Health status is determined by a range of factors, including access to healthcare, socioeconomic variables, working and living conditions, and cultural environment (6, 18). Universal health coverage is necessary in order to reach the Millennium Development Goals (MDG) to reduce poverty and achieve sustainable development. The goal for universal health coverage is rooted in politics and international law, and is a human rights issue (19). The 1948 declaration of human rights states that everyone has the right to an adequate standard of living for health, including medical care (20). Primary healthcare should be available irrespective of ability to pay. According to the CRPD, “Persons with disabilities have the right to the highest attainable standard of health without discrimination on the basis of disability.” (Article 25) (5). Persons with disabilities have general healthcare needs like the rest of the population, but they also have special healthcare needs (6), these include the prevention of secondary conditions, physical rehabilitation, and prosthetic and orthotic services.

Physical rehabilitation medicine is a specialisation, and provides a health strategy to address disability (21). The world report on disability defined

rehabilitation as “a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning of individuals in interaction with their environments” (6). Improving function is achieved through treatment of health conditions, reducing impairment, and treating or preventing complications. Barrier removal in society is not considered to be rehabilitation (6, 21). Rehabilitation services include technological intervention such as prosthetic and orthotic services (22). Rehabilitation is cross-sectorial and carried out by health professionals. It also often involves non-specialist workers such as community based rehabilitation workers and family members (6). Rehabilitation medicine physicians are described as the leaders and coordinators of interventions in high-income countries (22). Specialised rehabilitation physicians were not available in most African countries. In sub-Saharan Africa, only six rehabilitation physicians were identified in 2009, all residents of South Africa (23). General practitioners and other professions were often involved in the main tasks of physical rehabilitation (22). Low- and middle-income countries also had an insufficient supply of other health-related rehabilitation professionals such as prosthetists/orthotists (24), therefore the number of professions that are included in the rehabilitation team in developing countries varies.

The International Classification of Functioning, Disability and Health (ICF) is a model of functioning (25) and a classification for various aspects of health. The ICF describes dimensions of health and some health-related components of well-being (26). Figure 2 illustrates the ICF model that includes, body functions and structures, activity, and participation. Functioning is also dependent on personal factors and environmental factors. The ICF model is based on a biopsychosocial perspective of functioning in order to integrate medical perspective and a social perspective on disability (26). The ICF model facilitates an interdisciplinary approach, in which interaction between the individual and the environment is in focus, as well as how the individual and his/her family function and participate within their particular social and cultural context. According to the ICF classification, products and technology such as prosthetic and orthotic devices are environmental factors (26). Other environmental factors are natural

environment, support and relationships, attitudes, and service systems and policies. According to the ICF, activity “is the execution of a task or an action by an individual” and participation is, “involvement in a life situation” Mobility in this thesis is according to the ICF classification defined as “moving by changing position or location or by transferring from one place to another by walking and by using various forms of transportation” (26).

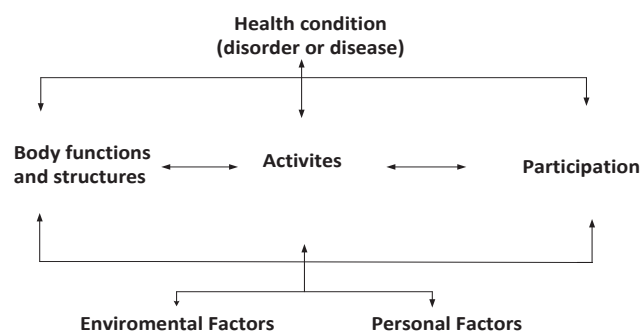


Figure 2: Interactions between components of the ICF, WHO 2001(26).

Disability is defined as impairments, activity limitations, and participation restrictions (26). It refers to the negative aspects of the interaction between an individual with a health condition and that individual's personal and environmental factors (6, 27). According to CRPD, Article 1, persons with disabilities “include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others” (5). This thesis mainly concerns persons who have lower-limb impairments, reduced mobility, and are in need of prosthetic or orthotic devices. Based on data from the World Health Survey and Global Burden of Disease 2002-2004, which includes 59 countries, it was estimated that approximately 15% of the world’s population were living with a disability. According to the World report on Disability 2011, about 2-4% (110-190 million people), experience significant difficulties in functioning (6).

Poverty, health, and disability

The broader view of poverty goes beyond considerations of financial resources and includes access to health, education, housing, and social inclusion (28). Poverty is a determinant of health (29). Disability is associated with poverty (30), and people with disabilities are overrepresented among the poor, who are at greater risk of suffering from illness or disability and less able to access healthcare. A vicious circle can be created by disability and poverty.

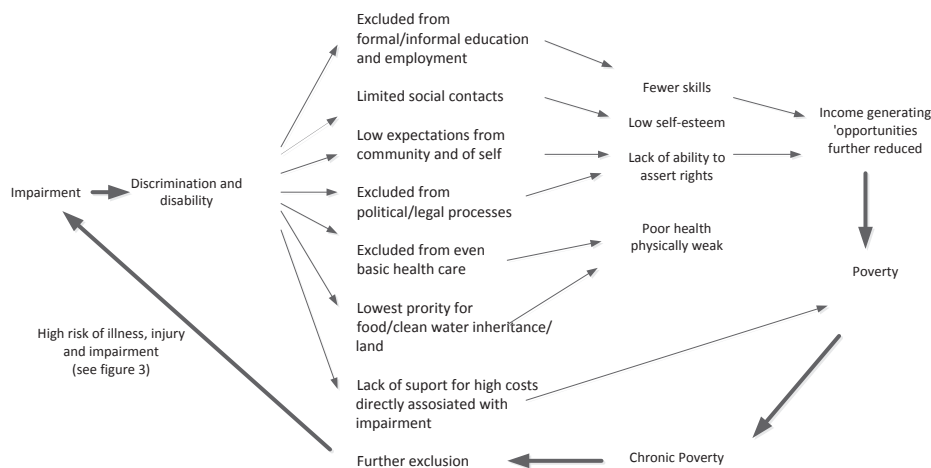


Figure 3: Disability and poverty circle (31) (Reprinted by permission of Elsevier, Rebecca Yeo, and Karen Moore).

Figure 3 illustrates how persons with disability have an increased risk of being poor. Disability can lead to discrimination, which in turn leads to exclusion and limited access to education, employment, social contacts, political processes, healthcare, food, and clean water. This leads to fewer skills, low self-esteem, and the inability to access basic rights. Lack of support for costs directly related to persons with impairment, such as those in need of assistive devices and rehabilitation services, leads to reduced mobility (31).

Disability or illness can remove individuals from activities and social roles, including work and relationships, and this involves a major change of status (32). Persons with disabilities have costs related directly or indirectly to their disability. A separate poverty line for the families of persons with disabilities has been suggested, based on the results of the World Bank's poverty assessments survey (33). This was also due to the fact that income-generating opportunities were further reduced and that persons with disabilities often lived in chronic poverty. In low income countries, persons with disabilities had higher medical expenditures, lower education attainment (30), and lower employment rates (34) than persons without disabilities.

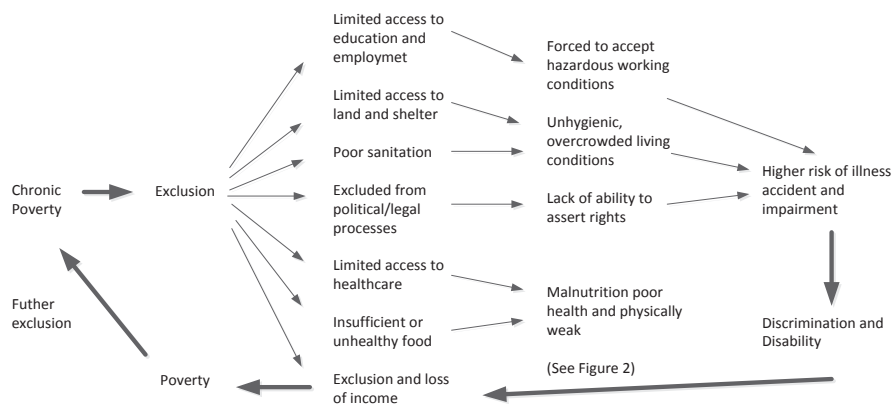


Figure 4: Poverty and disability circle (31) (Reprinted by permission of Elsevier, Rebecca Yeo and Karen Moore).

Figure 4 illustrates the obverse of Figure 3; namely, how poverty and disability are interlinked. Being poor increases the likelihood of being excluded from education, employment, and healthcare. This increases the risk of sustaining an impairment and becoming a person with a disability (31). Poverty can also lead to secondary disabilities for those individuals who are already living with a disability.

Several studies have demonstrated the association between disability and poverty (30, 33, 35). There were, however, contradictory findings in a few

studies reviewed in the World report on disability, which indicated that being a person with a disability does not necessarily increase the probability of being poor in a developing country (6). In a household survey, the association between poverty and disability disappeared in most of the 14 developing countries when controlling for schooling (36). This indicated that access to education for persons with disabilities can reduce the link between disability and poverty (36).

Data related to disability and poverty was limited for the countries included in this thesis. However in Malawi, households which included persons with disabilities had a lower income than households which did not (37). In Sierra Leone, very few persons with a disability had access to employment, and the majority survived by begging, through goodwill, and assistance from charitable organisations (38). At the same time, households in Sierra Leone who had a person with a severe disability spent more money on healthcare than households without (39). Persons with disabilities often face difficulties in resettlement after conflict. In Sierra Leone, the government donated land outside urban areas for development organisations to build housing for persons with disabilities. This reduced opportunities for persons with disabilities to integrate into society, attend school, and gain employment, which subsequently contributed to further exclusion (40).

Human rights

The purpose of the CRPD developed by the United Nations General Assembly in 2006 “is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (Article 1) (5). The CRPD reflects a shift in the way disability is seen. Historically, it has been viewed as a personal condition which affects an individual, and can be improved by medicine or rehabilitation. This reflects a medical approach, where services in low income countries often have been provided through charity and welfare programmes. In contrast, the CRPD reflects a biopsychosocial perspective which includes both social considerations and a medical perspective on disability (41). The CRPD focuses on the interaction

of the individual with an environment as well as the right to health, rehabilitation and assistive technology. The international CRPD from 2007 builds on the United Nations Standard rules on Equalization of Opportunities for Persons with Disabilities.

United Nations Standard Rules on Equalization of Opportunities for Persons with Disabilities

In 1994, the General Assembly adopted the Standard Rules on Equalization of Opportunities for Persons with Disabilities (42). Rule 3 affirms that “states should ensure the provision of rehabilitation services to persons with disabilities in order for them to reach and sustain their optimum level of independence and function”. Rule 4 states that assistive devices should be available for those who need them. States should support the development, production, and distribution of assistive devices. “Assistive devices and equipment should be provided free of charge or at such a low price that persons with disabilities or their families can afford to buy them” (Rule 4). Prosthetic and orthotic devices enable persons with disabilities to achieve personal mobility and independence. Access to assistive devices can contribute to facilitating access to human rights and living with dignity (6, 42).

In 2004, ten years after the publication of the Standard Rules on Equalization, a survey (43) was carried out to assess the global situation for persons with disabilities. One hundred and ninety-one member states of the United Nations were targeted, and surveys were sent to the governments and to two national disability organisations in each country. One-hundred and fourteen countries responded. The findings indicated that, in general, there were many good intentions worldwide, but they were not necessarily backed up by political will and allocation of resources. The survey showed that 50% of responding countries had not taken action on all measures required to provide rehabilitation or support services, including provision of assistive devices. Only one organisation for persons with disabilities in Malawi and one organisation for persons with disabilities in Sierra Leone filled in the questionnaire. No response was provided from Pakistan. Malawi, Sierra Leone, and 33 other countries indicated that they had not supplied

individuals with assistive devices, and 49 countries had not taken any action on accessibility, for example, to ensure accessibility to buildings for persons with disabilities (43).

In the same year 2004, an African Disability and Rehabilitation Status report, which included 29 African countries, was published by the disability and rehabilitation team of the WHO (44). The team reported that, in a few countries, assistive devices such as prostheses and orthoses were provided free of charge to users through government funds or external donors. In other countries, users themselves had to contribute, but the largest portion was covered by the government. Furthermore, in another group of countries, users were asked to pay in accordance with their income. All countries reported that they could not provide services to everyone, and that services which included possibilities for maintenance and repairs were lacking in rural areas. In Malawi, the disability and rehabilitation status report of 2004 indicated that only 11% of persons with disabilities had access to medical and rehabilitative care. Many countries in the world have, however, made very little progress since 1994. In order to address this shortfall, the CRPD was launched in 2007 by the United Nations (5).

Convention on the Rights of Persons with Disabilities

While the Standard Rules on Equalization uses the term 'Rule', the CRPD use the term 'Articles'. Those Articles related to prosthetic and orthotic services are presented in Table 2. In the convention, states are obligated to promote the availability of assistive devices and mobility aids such as prosthetic and orthotic devices, provide services, and offer training for staff to deliver services (Article 4). The CRPD asserts that persons with disabilities have the right to personal mobility, so as to ensure independence, and rehabilitation services, including provision of prosthetic and orthotic devices and training. It further indicates that states must make quality mobility aids such as prosthetic and orthotic devices accessible and affordable (Articles 20 and 26) (5).

Table 2: Convention of Rights of Persons with Disabilities (5)

Article 4 - General obligations	
(g)	“To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communication technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost.
(h)	To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities.
(i)	To promote the training of professionals and staff working with persons with disabilities in the rights recognized in the present Convention so as to better provide the assistance and services guaranteed by those rights” (5).
Article 20 - Mobility	
“States Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by:	
(a)	Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;
(b)	Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;
(c)	Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities
(d)	Encouraging entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disabilities.”
Article 26 - Habilitation and rehabilitation	
1.	“States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:
(a)	Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;
(b)	Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.
2.	States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.
3.	States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.”
Article 6 – Women with disabilities	
1.	“States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.
2.	States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.”

The table includes only the four most relevant articles for this thesis; the convention includes 50 articles in total.

Accessibility includes non-discrimination, and access in both a physical and informative sense (45). Affordability refers to the ability to cover the associated costs (46). The CRPD further indicates that habilitation and rehabilitation should be available to women with disabilities, as well as to persons with disabilities living in rural areas (Article 4 and 26) (5). In 2013, 158 out of the 193 member States of the United Nations had signed the convention (5). The CRPD is monitored at both national and international levels. At the national level, governments are expected to appoint at least one person to address matters related to implementation of the CRPD. A national human rights institution to promote, protect, and monitor the convention should also be established (5). The Committee on the Rights of Persons with Disabilities is the international body of experts who monitor implementation of the Convention by states (5).

Reviews of the Conventions of Human Rights, including CRPD in the countries included in this thesis

All states who have signed and ratified the CRPD are obliged to submit regular reports to the committee on how the CRPD is being implemented. States must initially report within two years of accepting the Convention, and thereafter every four years. The Committee subsequently examines the reports and makes suggestions and general recommendations as they consider appropriate. These are forwarded to the states concerned. The Optional Protocol to the Convention gives the committee authority to examine individual complaints with regard to violations of the Convention by states (5). Prior to the CRPD the rights for persons with disabilities were included in the general conventions of human rights.

Malawi has signed and ratified the CRPD, and the country's initial report on disability to the United Nations was due in 2011. Report submitted to the Human Rights Council to date, however, have included no data on disability (47) or service provision for persons with disability in Malawi (48). Concerns about the situation for women were highlighted, as Malawi had discriminatory family laws such as multiple marriage and child marriages. The report also stressed concerns for women in rural areas who had limited access to healthcare, education, land ownership, and inheritance (47).

Sierra Leone has also signed (49) and ratified the CRPD (13). The Sierra Leone report for the Human Rights Council in 2011 reflected that while human rights issues have been addressed on the political agenda and several programmes to protect women have been implemented, many issues remain (13). After being reviewed by the Human Rights Council, many recommendations were made, but disability was not named as one of the main areas requiring attention. The chief recommendations in the area of health and disability were identified as torture, women's and children's rights, maternal care, female genital mutilation, unsafe abortions, and child marriages (50).

In August 2011, Pakistan ratified the CRPD (51). Concerns were raised during the universal periodic review in 2012 that persons with disabilities had limited access to support which could allow them to participate with education, access health services, and participate in cultural activities. Concerns were also raised in relation to the fact that people with disabilities were excluded due to attitudes and common behaviour in the society. The recommendations were related to a need for Pakistan to take responsibility and not rely on charity-based organisations to provide services to persons with disabilities (52).

Perspectives on rehabilitation for persons with disabilities

The World report on disability produced by WHO and the World Bank clearly placed disability within a human rights perspective, and argued that disability should not be seen from purely medical or social perspectives (6). The CRPD supports the ICF developed by the WHO, and considers disability and functioning as a dynamic interaction between health conditions (individual) and contextual factors (environment); see Figure 2 (26). Prosthetic and orthotic devices are, according to the ICF, environmental factors which can improve a person's function. When implementing the CRPD, it is also necessary to address the need for assistive technology. The aims of providing prosthetic and orthotic devices and

services are: 1, increased function and mobility (medical perspective); 2, increased activity and participation in society (ICF perspective).

The influence of culture on beliefs related to illness and disability

In this thesis, countries with varied cultures are included, and those cultures influence how people view and treat persons with disabilities. The concept of culture is complex, and in everyday usage has differing meanings (53). Taylor's definition of culture states that "Culture or civilisation taken in its widest ethnographic sense is that complex whole which includes knowledge, belief, art, morals, custom, and other capabilities and habits acquired by man as a member of society" (53). Studies of culture can offer important insights into the socio-cultural aspects of disability studies (54). Perceptions of disability and personal, social, and practical consequences of impairment will differ depending on cultural factors (54). One focus when studying cultures can relate to what makes groups of people different from each other (53). An alternate focus can be to investigate what is similar and unites different groups of people, or what is universal and unites humanity on a deeper level. Human rights and the CRPD are seen as being universal, designed to be culturally neutral, and applicable in cross-cultural settings (54). However cultures are varied, and this affects how disability is viewed. Consequently, it is vital to consider this fact when implementing rehabilitation services.

Peoples' understanding of disease and disability and its causes are dynamic and sometimes incoherent (32). According to Cormandoff, dysfunctions of the body, as represented by illness (32) or disability, disrupt the harmony between the physical, social, and moral being. People give meaning to illness and the experience of disability by drawing from multiple sources (32). Discussion in speech and writing in society about illness, disease and disability, cultural resources and beliefs, as well as expert discourses including biomedicine and traditional medicine, all affect how a person with a disability is viewed in society. Biomedicine is a branch of medical science concerned with the capacity of human beings to survive and function in

abnormally stressful environments, and through the protective modification of such environments (55). Traditional medicine, according to the WHO, consists of knowledge, skills and practices based on the theories, beliefs, and experiences belonging to different cultures, and is used for the maintenance of health or treatment of illness (56). Societies' understanding of disability varies in response to knowledge, personal experience, and traditional beliefs. Most people develop health-related beliefs from folk-models of illness, biomedicine, traditional medicine, and in consultation with friends and family. People draw selectively from these sources of information, and the dominance of each can vary within different societies. It is well-established that beliefs may affect patients' compliance to medical professionals' instructions and contribute to misunderstandings (32). People who are illiterate build their beliefs and knowledge only through verbal information, making them more prone to society's prevailing norms and beliefs. This also has an impact on their way they view disability.

A study from Malawi revealed varied explanations for the cause of disabilities. These explanations included illness, disease, the will of God, and witchcraft. However, all persons except one with disabilities in the study, were well cared for within their families (57). In Sierra Leone, amputees embodied memories of the civil war, and this affected their position in society and identity (58). The belief that disease or disability was caused by witchcraft and negative traditional beliefs was common in Sierra Leone, particularly in rural areas, leading to exclusion from society (38, 59, 60). For example, research based in Sierra Leone indicated that some people in the society believed that leprosy was caused witchcraft (61), and impairments were the fault of the witches or spirits. One study indicated that people with a mobility disability in Sierra Leone preferred to live in segregated communities in which they were not made to feel ashamed, and often did not wish to return to their own communities (59). In Pakistan, negative attitudes, along with myths and superstitious beliefs, existed towards persons with disabilities (62, 63).

Gender inequalities

Women with disabilities often faced double discrimination and had less access to health and rehabilitation services (38, 39). Gender is the social

construction of female and male distinction (53), and is related to how females and males interact in groups. Research within a social construction approach is about investigating gender from social, organisational, and cultural categorisation viewpoints (64). In Malawi, women with physical disabilities reported problems with using public transport and a lack of support from non-disabled people (57). Another study in Malawi indicated that men married women with disabilities, but left when their sexual needs were satisfied or the women got pregnant. The women with disability in the study expressed a desire for legislation that makes the fathers of their children economically responsible, even if they leave the woman (65).

Sierra Leoneans were, in general, poor, but the women were poorer (66), had less educational opportunities (39, 67), and lower literacy rates than men (66). Females with disabilities also had fewer possibilities to attend school; 50% of females and 34% of males included in a study with disabilities in Sierra Leone had never attended school (39). Many women in Sierra Leone suffered from birth complications, complications related to genital mutilation, lack of healthcare, and a maternal mortality rate which is 2.7 times higher than the average in Africa (66). Women with disabilities in Sierra Leone have also been shown to have less access to public healthcare as compared to men with disabilities (68).

Amongst the general population of Pakistan, there were wide gaps between men and women in terms of access to education, employment, and healthcare (69). Gender inequalities existed not only in respect to the accessing of services, but also in terms of basic rights. The Pakistani culture reduces women's mobility and hinders them from participating in development programmes, employment, and healthcare (70).

Inclusion in mainstream services

Education and healthcare are examples of mainstream services which are provided to citizens. Persons with disabilities have general healthcare needs, but are often excluded from mainstream service development programmes (31). In order to address this issue, persons with disability should be targeted

in policies and policymaking (31). The first MDG is to eradicate extreme poverty and hunger (71). This goal, however, cannot be achieved without taking persons with disabilities into consideration, as this group is so disproportionately over represented among the world's poorest people. To address this issue, a rights-based approach is necessary, where persons with disabilities can be included in mainstream services such as education, healthcare, and non-governmental organisation activities (31). In addition, access to special services, such as provision of assistive devices and associated services, is required. Generally, there is a lack of consideration for disability within the MDGs, and vulnerable groups such as persons with disabilities need to be included in such policies (46). Negative attitudes towards persons with disabilities in Malawi, Sierra Leone, Uganda, and Ethiopia were perceived to be a large obstacle to overcome in order to facilitate the inclusion of persons with disabilities into mainstream services (72-75).

Poverty Reduction Strategy Papers (PRSP) is a concept developed by the World Bank and International Monetary Fund (IMF). Low income countries develop national plans, called PRSPs, so as to reduce poverty and improve the living conditions for their citizens. When the PRSPs are established, the country can apply for grants, loans, or new credits from the World Bank and IMF. PRSPs are an important tool to achieve the aims at a national level (76). The inclusion of persons with disabilities has been poor while developing PRSPs in many developing countries (77, 78) including Malawi (79). The Malawian poverty reduction plan, reflects a charity model (79). This being said, persons with disabilities have the same rights and obligations as every other citizen in the constitution of the Republic of Malawi. A national policy on Equalisation of opportunities for persons with disabilities was adopted in 2006. Despite this, it has been demonstrated that persons with disabilities had difficulty accessing education and healthcare (80). Persons with disabilities need an income, even when they are not able to get this through employment. In South Africa's Eastern and Western Cape regions, which neighbour Malawi, persons with disability received financial grants from the government. A household survey from these regions (81) reported that there were no differences in mean household income between

those with and those without a family member with a disability. However, a higher proportion of persons with disabilities had never attended school and were unemployed when compared to persons without disabilities.

In recent years, progress has been made through the passing of a disability policy and Person with Disability Act (2011) in Sierra Leone, which makes provision for the establishment of a disability commission (72, 82). Pakistan adopted its National Policy for Persons with Disabilities in 2012, aiming to provide “an environment that would allow full realisation of the potential of people with disabilities through inclusive mainstreaming and providing them full support by the government, private sector and civil society”. However, according to the International Committee of the Red Cross (ICRC), little has yet been achieved in regard to physical rehabilitation programmes (83).

Prosthetic and orthotic services

Orthotic and prosthetic devices, crutches, and wheelchairs are common types of devices which facilitate or enhance users’ mobility. Wheelchairs, walking frames, and tricycles are not included in the scope of this thesis (45). A prosthetic device is an externally applied device used to compensate for the absence or loss of a body structure and body functions (4, 22). An orthotic device is an externally applied device to stabilise, improve, or restore impaired body functions and structure, related to the neuromuscular and skeletal system (4, 22). Both prosthetic and orthotic devices can also prevent medical complications and impairments (22). Prosthetic and orthotic service provision is related to the technical interventions offered to individuals with disabilities. Prosthetic and orthotic services are delivered by prosthetists/orthotists who design, measure, and fit prostheses and orthoses, and by prosthetic/orthotic technicians who manufacture prostheses and orthoses, ideally under the direction of a prosthetist/orthotist (4). The provision of prosthetic and orthotic services requires both medical and technical knowledge on behalf of the clinician (84). According to the definitions in international standards prosthetic and orthotic service delivery includes; patient assessment, casting and measurement, cast modification and rectification, manufacturing of prosthetic and orthotic devices, bench

alignment, static and dynamic alignment, finishing, and product delivery (4). Prosthetic and orthotic services also need to include follow-up and repairs of devices (84). The process of prosthetic and orthotic services delivery is described in Table 3.

Table 3: Process of prosthetic and orthotic service delivery

Definitions	
1.	Prosthetic and/or orthotic assessment is the “review of the overall condition of the patient by those involved in the treatment and the recommendation by the prosthetist/orthotist of the components and clinical fitting procedures best suited to the circumstances of that patient”(4).
2.	Prosthetic and/or orthotic casting and measurement is the “acquisition and recording of all information required to construct the prosthesis and/or orthosis by means that may include the preparation of diagrams, tracing, measurements and negative casts of the body segments”(4).
3.	Cast modification is the “process of modifying the positive model obtained by filling a negative cast in order to obtain a shape that specifies the whole or part of the form of the final prosthesis or orthosis”(4).
4.	Model modification/rectification is the process of changing a model from its anatomical shape to a functional biomechanical shape.
5.	Fabrication of prosthetic and/or orthotic device
6.	Bench assembly and alignment is the “assembly and alignment of the components of prosthesis or orthosis in accordance with their characteristics and with previously acquired data regarding the patient”(4).
7.	Static alignment is the “process whereby the bench alignment is refined while the prosthesis or orthosis is being worn by the stationary patient”(4).
8.	Dynamic alignment is the “process whereby the alignment of the prosthesis or orthosis is optimized by using observations of the movement pattern of the patient”(4).
9.	Finishing are the “manufacturing processes performed after dynamic alignment in order to produce the prosthesis or orthosis in its final state”(4).
10.	Product delivery is the “process of verifying that the finished condition of the prosthesis or orthosis including fit, functioning, and appearance is satisfactory”(4).
11.	Follow-up services is the process of investigating if the prosthesis/orthosis functions as intended, as well as monitoring the results or consequences of the intervention (3), including regular check-ups that can be through community based rehabilitation programmes (84).
12.	Repair services is the process of restoring the prosthesis or orthosis to a well functional sound condition after damage.

The goal of prosthetic and orthotic service delivery is to enable persons with health conditions that involve physical disability to achieve and maintain optimal function. This should include function in terms of both mobility and interaction with their environment (6, 22, 26). Further goals are to reduce impairment, prevent complications, and to ensure access to rehabilitation services as a human right (5). The prosthetics and orthotics profession is part

of the multi-professional physical rehabilitation medicine team. The services provided are dependent on cooperation between the prosthetist/orthotist, patient (21), and other professionals. Rehabilitation efforts, such as gait training, are essential (84). Prosthetists/orthotists are not available in many cities in developing countries, and provision of crutches in lieu of prosthetic and orthotic devices is common. Where prosthetic and orthotic services are available, the level of access to rehabilitation training with a physiotherapist varies.

Studies in Malawi, Mozambique, Namibia, Zambia, and Zimbabwe have addressed the living conditions of people with disabilities and shown large gaps in the provision of assistive devices such as prosthetics, orthotics, and related services. These studies also found that only 17-37% of people who needed an assistive device actually received one (6, 85). The proportion of women who had access to an assistive devices was lower than that of men in Malawi (14% and 25%, respectively) and in Zambia (12% and 16%) (6). Corresponding figures from Sierra Leone and Pakistan were not found in the published literature. The availability of vaccines has reduced the incidence of polio in Malawi, and therefore reduced the number of persons with disabilities (44). It is well understood, however, that the conflict in Sierra Leone resulted in an increase in the number of amputees and persons affected by polio, two groups which typically require prosthetic or orthotic devices (40). In 2005, Pakistan was affected by a major earthquake and, in a retrospective survey, it was concluded that lower-limb injuries were the most common resulting injury, and about five percent of those injured were in need of assistive devices (86).

Appropriate technology for prosthetics and orthotics in developing countries

The WHO action plan for 2014-2021 has the objective of strengthening and extending rehabilitation services and assistive technology (11). A recent initiative which sought to implement the WHO action plan was the multiagency Global Cooperation on Assistive Technology scheme, which was launched in 2013 and focused on improving access to assistive technology (87). A literature review of lower-limb prosthetic technologies in

developing countries indicated that product evaluation of assistive devices was performed, but further research and product development was needed (88, 89). Furthermore, there was a particular need for research related to policy, service delivery, and patient outcomes (89). Studies with a focus on service delivery and outcomes in relation to lower-limb prosthetics and orthotics have been conducted in Vietnam (90, 91), India (92), and Haiti (93, 94). A survey of staff providing prosthetic and orthotic services from a number of low income countries indicated that the development of improved designs for low-cost and durable components, in particular prosthetic knees and feet, needed to be addressed. Poor alignment of prosthetic and orthotic devices was also widely reported (10).

Appropriate technology for developing countries needs to be affordable and must suit the environment of the user. Various low-cost technologies for prostheses and orthoses exist. Examples include the Jaipur foot (95), Shape and roll foot (96), and traditional metal orthoses. Polypropylene technology, developed by the ICRC, is a commonly used low-cost technology in developing countries for the production of prosthetic and orthotic devices (97, 98). Roughly 396,000 prostheses and 454,000 orthoses have been delivered within ICRC's own physical rehabilitation programmes since 1979 (83). Other non-profit organisations, such as Handicap International and Exceed, have projects in developing countries that buy ICRC components and deliver prostheses and orthoses which incorporating the technology. The countries included in this thesis commonly used ICRC low-cost polypropylene technology for producing prosthetic and orthotic devices. Traditional metal bar orthoses were also produced in Malawi and Sierra Leone, most commonly for polio patients.

Patients' mobility and satisfaction of assistive device and service delivery

Several studies have investigated various aspects of mobility while using prosthetic and orthotic devices produced with ICRC polypropylene technology (90, 91, 97, 99, 100). The majority (66-100%) of prosthetic users had the ability to walk for more than one kilometre (97, 99, 100). A study from Vietnam, which investigated below-knee amputees provided with

prostheses, found that patients used their devices an average of eight hours a day and that 2% of participants reported pain while using their prosthesis (91). Methods of using the ICRC technology are taught within prosthetic and orthotic education programmes in developing countries. These services are best provided by clinicians who have received training within the field of prosthetics and orthotics (101, 102).

Satisfaction with lower-limb prosthetics and orthotics has been investigated in three studies from Vietnam (90, 91, 99). Two of the studies indicated that 10% or less of patients were dissatisfied with their ICRC polypropylene prosthesis, while the third reported that amputees had limited ability to perform rigorous physical activity but were relatively satisfied with their prosthesis. The majority were satisfied with the service they received (90). The instrument used in these studies included only one general question about satisfaction with the prosthesis (90, 91, 99). A qualitative study in Haiti, which used individual interviews, focus group interviews, and observations of amputees, indicated that almost all patients expressed gratitude that prosthetic services were offered to them for free (94). A small study in India, including only five orthotic patients with post-polio syndrome, indicated that the design of orthotic devices had an impact on patient mobility and satisfaction (92). In Iran, where both high- and low-cost technologies were used for the production of prostheses and orthoses, patients were dissatisfied with the durability and cosmetic appearance of the device, and complained that the assistive devices tore their clothes. Patients indicated high levels of satisfaction for fit and ease of donning the assistive device, but were dissatisfied with the process of service delivery (103). In summary, studies investigating patients' capability, mobility, and satisfaction with their assistive device, along with patients' satisfaction with service delivery using low-cost technology in developing countries, were very limited (104).

Education for prosthetic and orthotic personnel

The WHO, together with the International Society for Prosthetics and Orthotics (ISPO), has divided the education of personnel involved in the production and supply of prosthetic and orthotic devices into three

categories: Category I; prosthetists/orthotists with 3-4 years of university level education, including both theoretical and practical components; Category II, orthopaedic technologist with 3-4 years of university level education, including a large practical component; Category III, technicians/bench workers who have completed a 1 year course (105). The Tanzania Training Center for Orthopedic Technologists (TATCOT) in Tanzania trains people from roughly 20 English-speaking African countries. Graduates work in many different African countries, including Malawi and Sierra Leone. There are different courses offered at TATCOT (Category I, II, and III), all of which are accredited and recognised by both ISPO and WHO. As part of a continual quality improvement process, it is necessary to determine if the current educational standard is meeting the needs of the disabled population, and to determine specific areas that could be improved or further developed within the current education.

The Pakistan Institute of Prosthetics and Orthotics Science (PIPOS) is one of three educational institutions for prosthetists/orthotists in Pakistan (106). Another, the School of Prosthetics and Orthotics, was established in 2007 in Karachi. These two institutions offer programmes which are ISPO/WHO category II-recognised and include three years of academic studies (63). ISPO regularly evaluate the education programmes. A Category II inspection of PIPOS conducted in 2005 recommended that improvements be made to student assessment methods, access to resources, education in biomechanics, and in the amount of exposure to a multidisciplinary working environment (107). Education inspections did not review graduates or employers views about whether the quality of the education met their specific needs or the needs of the Pakistani community. The third education programme, announced by Rawalpindi Medical College in Islamabad focuses on orthotics only (106).

Rationale

To facilitate personal mobility for persons living in developing countries, the CRPD promotes availability, knowledge, and use of assistive devices. This includes access to prosthetic and orthotic services and rehabilitation programmes (Article 26 and 20) (5, 8). Despite efforts from international, national, and local stakeholders, mobility needs for all are not being met, as the scale of the services for delivering assistive devices does not correspond to the need (6, 45). In order to implement the CRPD, the quality of prosthetic and orthotic services in low income countries is of concern. Little research related to prosthetics and orthotics in low-income countries was available (8, 108), including outcomes related to the provision of orthotic devices (109, 110) and related service delivery (108). In the research that does exist, most studies have been directed towards evaluating specific products (88, 89, 109). Few studies have investigated overall satisfaction with prostheses fabricated using low-cost technology (109), and studies including a detailed analysis of factors which influence patient satisfaction with assistive devices and with service delivery were, to the knowledge of the author, not available from low-income countries. Evidence-based recommendations for prosthetic and orthotic services in low-income countries were needed in order to more effectively provide services to persons with disabilities (111). As a result, aspects related to quality of assistive devices and services have been investigated in this thesis.

Many organisations which deliver prosthetic and orthotic services in developing countries use the number of prosthetic and orthotic devices they have delivered as measure of success to report to donor organisations. Using only the number of appliances delivered, however, is a poor indicator, as it does not reflect the quality of the assistive device (111), nor does it give any indication if the device is assisting with mobility or facilitating inclusion in daily activities (112). Efforts have been made by ministries of health and international organisations to provide prosthetic and orthotic services in Malawi, Sierra Leone (111), and Pakistan. To date, no studies have investigated if patients who require prostheses or orthoses in these countries

are satisfied with their assistive devices and the services received; nor have any studies assessed their mobility.

In addition to investigating patient satisfaction, it is also of interest to explore facilitators, barriers, and suggestions for improvements to the provision of prosthetic and orthotic services from the perspective of local professionals. The level of education of prosthetic and orthotic staff, as well as cultural aspects, are factors that could potentially affect prosthetic and orthotic service delivery. The number of locally trained prosthetists/orthotists in developing countries including Malawi, Sierra Leone, and Pakistan was too few to be able to provide prosthetic and orthotic devices to all of the persons in need of services (105, 109). Subsequently, it is essential that the curricula of existing education programmes maintain quality, and reflect the demands that clinicians have placed upon them in low income settings. Efforts have been made in Malawi, Sierra Leone, and Pakistan to provide assistive devices and associated services. Despite this, the number of patients receiving prosthetic and orthotic services was alarmingly low (6, 44). The knowledge generated in this thesis could be applied in order to improve low-cost prosthetic and orthotic designs, prosthetic and orthotic services, and education. Furthermore, this knowledge could also be used for policy-making.

Aim

The overall aim of this thesis was to generate further knowledge about prosthetic and orthotic services in developing countries. In particular, the thesis focused on patient mobility and satisfaction with prosthetic and orthotic devices, satisfaction with service delivery, and the views of staff regarding clinical practice and education.

The specific aims of each study were to:

- I. Investigate patients' mobility and satisfaction with their lower-limb prosthetic or orthotic device and related service delivery in Malawi, and to compare groups of patients regarding type and level of device and demographics.
- II. Investigate patients' mobility and satisfaction with their lower-limb prosthetic or orthotic device and related service delivery in Sierra Leone; compare groups of patients regarding type and level of assistive device, gender, area of residence, and income, and identify factors associated with patients' satisfaction of assistive device and services.
- III. Explore the experiences of prosthetic and orthotic service delivery in Sierra Leone from the local staff's perspective.
- IV. Explore areas in which the education at the Pakistan Institute of Prosthetic and Orthotic Science could be improved or supplemented, to facilitate the clinical practice of graduates, to describe the educational opportunities graduates have had since their graduation, and to explore their further educational needs.

Additional aims in the frame were to:

- V. Compare results from Malawi and Sierra Leone concerning patients' mobility and satisfaction with their lower-limb prosthetic or orthotic device and related service delivery.
- VI. Identify variables associated with patients' satisfaction with assistive devices and associated services in the combined data from Malawi and Sierra Leone.
- VII. Compare findings related to experiences of prosthetics and orthotic service delivery and education in Sierra Leone and Pakistan from the perspective of local professionals.

Method

Scientific perspective

Epistemology and methodology are intimately related to each other. Epistemology involves the *philosophy*, strategies of inquiry related to how we come to know the world, while methodology involves the *practice* of specific research methods (113). The approach to epistemology taken in this thesis was inspired by empiricism. Visits to many prosthetic and orthotic centres in many different developing countries have influenced the body of work. Research questions have been inspired by listening to staff talking about prosthetic and orthotic service delivery, and wondering how mobile and how satisfied the prosthetic and orthotic patients leaving the centres were. The design of studies has been inspired by both deductive and inductive reasoning, which can generate knowledge related to the overall aim from different angles (114). Deductive and inductive approaches are two broad ways of reasoning (115), and they are often assigned to different methodological approaches: Deductive reasoning is the process of reasoning from one or more general statements to more specific observations so as to reach conclusions. Deductive reasoning is concerned with testing or confirming specific hypotheses generated from theories or previous research results. In this thesis, a deductive approach has been used in Studies I and II. Inductive reasoning is initiated by specific observations, which in turn lead to the detection of patterns, broader generalisations, and theories. Inductive reasoning is open-ended and exploratory, particularly at the beginning (116). An inductive approach was used in Studies III and IV, where a qualitative methodology was adopted and individual interviews were employed in order to address the aims. In this thesis, methods were chosen on the basis of what was possible with the available resources.

Design

The present thesis has a descriptive, explorative, and comparative design, with use of quantitative and qualitative data collection methods. Study I was conducted in Malawi, Studies II and III in Sierra Leone, and Study IV in Pakistan. All four studies were based on empirical data from developing countries. Studies I and II investigated patients' perspectives of mobility and prosthetic and orthotic service delivery, while Studies III and IV explored and described the perspectives of local professionals. Studies I and II were based on questionnaires, and data was statistically analysed. Studies III and IV were based on qualitative individual interviews and content analysis was applied. Table 4 presents an overview of the studies.

Table 4: Overview of the studies

Study	I	II	III	IV
Design	Quantitative Cross-sectional Descriptive Comparative	Quantitative Cross-sectional Descriptive Comparative	Qualitative Explorative Descriptive	Qualitative Descriptive
Context	Malawi	Sierra Leone	Sierra Leone	Pakistan
Participants	83 lower-limb prosthetic and orthotic patients	139 lower-limb prosthetic and orthotic patients	15 prosthetic/ orthotic technicians	15 prosthetists/ orthotists
Data collection	Self-report questionnaires	Self-report questionnaires	Individual interviews	Individual interviews
Data analysis	Descriptive statistics, Chi- square tests, Mann-Whitney U tests, and Kruskal Wallis tests when comparing groups Linear regression analysis	Descriptive statistics, Chi- square tests, Mann-Whitney U tests, and Kruskal Wallis tests when comparing groups Linear regression analysis	Latent content analysis	Manifest content analysis

Sampling and participants

Sampling (Studies I and II)

Patients were recruited from the local registers at the prosthetic and orthotic centre in Lilongwe, Malawi (Study I), and from all four rehabilitation centres

in Sierra Leone (Study II). Malawi had two rehabilitation centres providing similar prosthetic and orthotic services. The centre in Blantyre, which was not included in the sample, used the same technology as the centre in Lilongwe. Staff at both centres had the same level of education. To be eligible to participate in Studies I and II, patients needed to be fifteen years or older, have a lower-limb disorder, and have received prosthetic and/or orthotic services between April 2009 and December 2010.

A total of 196 patients in Malawi (Study I) and 553 patients in Sierra Leone (Study II) fulfilled the inclusion criteria. In Malawi, contact details for 148 of the 196 patients were available from the centre's register. Attempts were made to contact 148 patients. Of these, a local staff member was able to contact 97 patients, who were asked to participate. Reasons for not participating are presented in Table 5.

In Sierra Leone (Study II), 139 patients were located and subsequently asked to participate. As only a few telephone numbers were available from the patient registers in Sierra Leone, local rehabilitation staff assisted in contacting patients through visits to homes, schools, workplaces, via community organisations, and through key people; see Table 5.

Table 5: Sample and patients, Studies I and II

	Malawi	Sierra Leone
Patients in register	196	553
Eligible patients asked to participate	97	139
Dropouts		
Illness	2	
Not being able to travel on public transport	3	
Said they would come but never did	9	
Patients included	83	139

Dropouts

In Malawi (Study I) and Sierra Leone (Study II), no statistically significant differences between the patients in the register who participated in the study (Malawi n=83 and Sierra Leone n=139) and those who did not (Malawi n=113 and Sierra Leone n=414) were found regarding sex, age, type of assistive device (prosthetic or orthotic), or level of assistive device (above-knee and below-knee). In Malawi (Study I), there was no significant

difference regarding region of residence, but in Sierra Leone (Study II) the relative number of patients representing Freetown, the capital city, was slightly lower than other regions. Based on the patient register, it was not possible to determine whether patients lived in urban or rural settings.

Patients' characteristics (Studies I and II)

Patients included in Studies I and II are presented in Table 6. In Malawi, 36 of the 83 patients (43%) were female, and 47 (57%) were male. The average age of Malawian patients was 36 years (range 16-74 years), and forty-three percent lived in the city of Lilongwe. In Sierra Leone (Study II), 39 of the 139 patients (28%) were female and 100 (72%) male. The average age was 34 years (range 15-81 years), and patients represented all four rehabilitation centres in Sierra Leone.

The majority of patients in Malawi and about half of the patients in Sierra Leone considered their overall physical health as good or very good. Fifteen percent of patients in Malawi and 37% in Sierra Leone said their mental health was bad or very bad. In Malawi, the majority had access to basic medical care, while the opposite was reported in Sierra Leone. The majority (90% in Malawi and 72% in Sierra Leone) had, at some point, attended school. Eighty-seven percent in Malawi and 60% in Sierra Leone could read and write. Roughly one third of the patients reported that they were currently working, including salaried work and self-employment (33% in Malawi and 39% in Sierra Leone). In both countries, approximately 90% percent did not have the possibility to eat three times a day, and about half of the patients had regular access to safe drinking water. The majority had a reasonable or adequate housing. About half of the patients were married, and 64% in Malawi and 70% in Sierra Leone had children (Unpublished data).

Table 6: Demographics and patient characteristics in Malawi and Sierra Leone

	Patients, Malawi n=83 (%)	Patients, Sierra Leone n=139 (%)
Sex n=222		
Female	36 (43)	39 (28)
Male	47 (57)	100 (72)
Mean age n=220	36	34
Rural/urban areas n=222		
Living in cities	41 (49)	86 (62)
Living in villages	42 (51)	53 (38)
Level of income n=222		
No income at all	36 (43)	49 (36)
Sometimes income	29 (35)	64 (47)
Regular income from employment	18 (21)	24 (18)
Ability to pay for costs associated with receiving the service appliances, accommodation travel n=222		
Yes	15 (18)	76 (55)
No	68 (82)	63 (45)
Type of assistive device n=221		
Prosthesis	64 (78)	79 (57)
Orthosis	18 (22)	60 (43)
Level of assistive device n=220		
Below-knee assistive device	44 (53)	49 (35)
Above-knee assistive device	39 (47)	90 (65)
General condition of device n=221		
Never used and Broken, cannot be used	9 (11)	20 (15)
In use but needs repair	41 (50)	64 (46)
In use, good condition	33 (40)	54 (39)
Hours assistive device is used per day n=211	9	9

Sampling (Studies III and IV)

Participants included in Studies III and IV were staff who were responsible for providing prosthetic and orthotic services. In Sierra Leone (Study III), participants were prosthetic and orthotic technicians trained at a Category III level according to the WHO/ISPO classification (105). This means that they are technical staff with apprenticeship-style training, or that they have two years of formal training with a focus on the fabrication of prosthetic and orthotic devices. In Pakistan (Study IV), participants were prosthetists/orthotists with Category II training, which involves three to four years of education, clinical responsibility for patient evaluation, design, and production of prosthetic and orthotic devices.

Sixteen of the 22 eligible technicians in the five rehabilitation centres in Sierra Leone (Category III) were present at the workshops when the study was to be conducted (2006 and/or 2011). They were all asked to participate, and one person declined because he did not have time.

Eligible participants in Study IV included one-hundred and two prosthetists/orthotists (Category II). Strategic sampling was used to recruit a broad selection of prosthetists/orthotists. To ensure a broad variety of participants, the sample included 15 representatives from each sex and different employment situations, including: 1) private practice; 2) governmental institutions; 3) international and national NGOs; 4) the international workforce; 5) people in the process of completing further studies abroad; 6) people who were unemployed.

Participants (Studies III and IV)

In Study III, conducted in Sierra Leone, eight prosthetic and orthotic technicians were interviewed in 2006 on the first visit by the author. Four of these original participants were re-interviewed during a second visit in 2011, together with seven new participants. The participants represented, in the first case, five rehabilitation centres and, in the second case, four. The average age of participants was 41 years (range 28–57 years), with an average work experience of 13 years (range 2–28 years). The participants were all male. Three participants had personal experience of a mobility disability and use of orthotic or prosthetic devices. Ten were from Sierra Leone, and one was from Liberia. Their training was varied, but thirteen were trained as prosthetic and orthotic technicians in Sierra Leone. Two participants had been enrolled at the Tanzania Training Centre for Orthopaedic Technologists for one year, studying either orthotics or wheelchair technology.

Study IV included fifteen graduates from PIPOS, including five females and ten males. The sex distribution (33% female; 67% male) of participants reflected the distribution of the study population. Persons interviewed had graduated from the school between 1999 and 2005. The average age was 26 years (range 23-30 years). Graduates had an average of 2.5 years' experience

(range 0.5-6 years). The interviewees represented the cities of Peshawar, Karachi and the North-West Frontier Province and Kashmir, which was severely affected by earthquakes in 2005. Those who had international experience had worked in East Timor, Saudi Arabia, and Cambodia. The participants worked with patients from both rural and urban areas, and three of them were teaching at PIPOS.

Instruments and translation procedures

Questionnaires (Studies I and II)

Questionnaires were used to address the aims of Studies I and II by examining a number of variables and the relationships between them (113). The questionnaires covered basic background information, questions evaluating patients' mobility, Quebec User Evaluation of Satisfaction with Assistive Technology questionnaire (QUEST), and specific questions related to satisfaction with prosthetic and orthotic devices and associated services. Patients could also add their own comments to the items.

In order to evaluate users' mobility with their assistive device, a number of specific questions were developed to reflect different gait situations that require varied levels of function when using prosthetic and orthotic devices. Six items under the umbrella of ability to walk (ability to rise from a chair; ability to move around in the home; ability to walk on uneven ground/roads; ability to walk up and down a hill; ability to walk on stairs) and two items related to the ability to use transport (ability to get in and out of a car; ability to get on and off a bus) were included. The response alternatives supplied were: Yes, without any difficulty; Yes, with difficulty; No, not at all; Not applicable.

QUEST comprises 12 items in total. Eight relate to user satisfaction with their assistive devices (dimensions; weight; ease of adjustment; safety; durability; simplicity of use; comfort; effectiveness), while four relate to service delivery (service delivery programme; repairs and servicing; quality of professional services; follow-up services) (117). QUEST uses a five level

response scale: 1) Not satisfied at all; 2) Not very satisfied; 3) More or less satisfied; 4) Quite satisfied; and 5) Very satisfied (117). QUEST is a standardised form which identifies the sources of user satisfaction and dissatisfaction in relation to assistive technology and service (117-119). The instrument is widely used with wheelchair users, with the objective of following-up on users' satisfaction (120, 121). QUEST has been demonstrated as a valid and reliable assessment tool (118, 119).

Specific questions related to prosthetic and orthotic rehabilitation services were generated from a literature review of relevant questionnaires, checklists, and clinical experience (122, 123). Questions about how often assistive devices caused pain and wounds/skin irritations were included. Additional questions were also asked about satisfaction with the assistive device and service, with particular reference: 1) The training received by the user to facilitate their usage of their assistive device. 2) The level of coordination of prosthetic and orthotic services with other rehabilitation professionals; 3) The look/appearance of the assistive device; 4) How easy it is to keep the assistive device clean; Finally questions about; 5) The user's ability to pay for costs associated with receiving the assistive devices and service; 6) Whether there was opportunities for the user to express their views about the assistive device to the prosthetist/orthotist; 7) Trust and confidence in the prosthetists/orthotists capability of delivering a quality service.

Translation of questionnaires (Studies I and II)

Permission was received from the Institute of Matching Person and Technology to translate the English version of QUEST 2.0 into Chichewa, spoken in Malawi (Study I) and Krio, spoken in Sierra Leone (Study II). The aim was to achieve Krio and Chichewa versions of the English instrument that were conceptually equivalent in the target countries and acceptable to the participants, and could be practically applied in the same way. To achieve this, the following steps were taken; forward translation, expert panel back-translation, pre-testing, and cognitive interviewing (124). The forward translation of the questionnaire from English to the local language was conducted by three different translators in Malawi and in Sierra Leone.

In Malawi, the translators had a background working in rehabilitation (Study I). In Sierra Leone (Study II), the translators were teachers working at the Sierra Leonean language department of the Freetown Teachers College.

Internal consistency/homogeneity for the QUEST sub-scales ‘satisfaction of assistive device’ and ‘satisfaction of service’ are presented in Table 7.

Table 7: Cronbach’s alpha QUEST 2.0

	Studies I and II				Reference Studies		
	Malawi English n=28	Malawi Chiche wa n=55	Sierra Leone English n= 62	Sierra Leone Krio n=77	English QUEST 2.0 (117, 125)	Dutch QUEST 2.0 (118)	Taiwanese QUEST (126)
Assistive device sub-scale	.73 (n=28)	.70 (n=49)	.75 (n=61)	.76 (n=76)	.80 (n=150)	.88 (n=2002)	.87 (n=105)
Service sub-scale	.69 (n=26)	.43 (n=44)	.68 (n=58)	.79 (n=73)	.76 (n=150)	.84 (n=2002)	.84 (n=105)

Note: A scale should preferably have a minimum of Cronbach’s alpha value of .7 (127).

Data collection

Surveys (Studies I and II)



Photo: Lina Magnusson

Figure 5: Data collection at rehabilitation centres in Malawi and Sierra Leone

Questionnaires were read to all patients because of low literacy levels. In Malawi, questions were read in English to 28 patients and in Chichewa to 55. In Sierra Leone, they were read in English to 62, in Krio to 77, and/or interpreted partly to another tribal language; either Kono, Themne, or Limba.

Questions were read to the patients in English by LM or in local languages by a trained research assistant. Figure 5 illustrates the data collection situation and triangular seating (128) that was used in cases when an interpreter was required. Data was collected between November 2010 and February 2011. In Malawi, data was collected at the rehabilitation centre (n=83), and in Sierra Leone in patients' homes or villages (n=32), in schools, workplaces, training centres (n=31), sports grounds (n=5), or at the rehabilitation centre (n=71).

For all patients, the general condition of assistive devices was evaluated by LM, a Swedish certified prosthetist/orthotist. The general condition of assistive devices were classified as one of; never used, broken cannot be used, in use but needs repair, or in use good condition.

Interviews (Studies III and IV)

Individual interviews were conducted in Sierra Leone and Pakistan with the staff who provide prosthetic and orthotic services. The questions used were open-ended, broad, and general so as to ensure that the participants expressed their views of the situation in order to be able to construct the meaning of a situation. In both Studies III and IV, an interview guide was used, and data was collected at the rehabilitation centres where the participants worked. Interviews were conducted in English.

Data analysis

Statistical analysis (Studies I and II)

In the planning phase, power calculations were performed for QUEST 2.0, satisfaction of assistive device, and service total scores in order to estimate how many participants should be included in Studies I and II. The power calculations indicated that approximately 160 patients should be included so as to detect differences between two groups with a power of 80%, given a true difference of 0.3 between groups. Previous research incorporating QUEST (117, 118, 120, 129) was used to estimate standard deviations.

These are, by necessity, approximations, since previous studies using QUEST 2.0 have been conducted on patient groups other than those included in this thesis.

In Studies I and II, statistical analysis was applied in order to analyse data from the questionnaire, including QUEST (117). Descriptive statistics were used to summarise results for all of the variables included in the questionnaire. The QUEST 2.0 manual (117) was followed when summarising QUEST total scores for satisfaction of assistive device and service.

Mann-Whitney U tests (two-sided) and Kruskal Wallis tests were used when comparing age, hours spent using the device, and satisfaction between groups of patients regarding type and level of device, sex, area of residence, and income (Studies I and II).

Chi-square tests were utilised when comparing proportions between groups. Due to the limited number of patients in Study I, the two responses 'Never used' and 'Broken, cannot be used' for describing a device's condition were combined into one when comparing the characteristics of the assistive device. In Study II, the 'Never used' option was not included in the analysis. In addition, the four response options 'Always' and 'Often', along with 'Seldom' and 'Never', which were used for questions related to whether the assistive device caused pain and wounds/skin irritations, were combined into two options in Studies I and II. This was also done in order to create a large enough group to facilitate a statistical analysis. The options 'Yes, with difficulty' and 'No, not at all' were combined into one due to small numbers when comparing mobility.

Linear regression analysis was conducted to explore which variables were associated with satisfaction of assistive device and services using the combined dataset (Studies I and II). Simple linear regression analyses of 23 variables was initially conducted separately for the two outcomes of sub-scale scores for satisfaction of assistive device and service. Variables with p-values of less than 0.1 were included in a multiple regression analysis with

backward elimination ($p < 0.1$). Final multiple regression analysis included variables with p-values of less than 0.1. Both variables relating to general condition of device were included in the final model, even though only one of them proved to be significant. Residual analysis was conducted on the final models, and showed linear regression analysis was appropriate for use.

Chi-square tests, Mann-Whitney U tests (two-sided), and t-tests (two-sided) were used to identify differences between patients in Malawi and Sierra Leone in relation to demographics, patient characteristics, condition of assistive devices, mobility, and satisfaction with assistive devices and service delivery. Only statistically significant differences between groups are reported in the results, and only p-values of less than 0.05 were considered to be statistically significant. SPSS 19 was used for statistical analyses.

Content analysis (Studies I, II, III and IV)

Content analysis of the message in interview texts is systematic, and can be both qualitative and quantitative. It summarises the characteristics of the message, rather than reporting all of the details of that message. Content analysis is growing in use and is a flexible methodology, as there are a variety of ways in which it may be applied (130). Quantitative deductive content analysis (131) was applied to qualitative comments in the questionnaires from Studies I and II. Qualitative content analysis was applied in Study III (132) and Study IV (133).

Analysis of open-ended questions in questionnaires

Quantitative content analysis is a numerical process, and has the goal of producing a numerically-based summary of the messages (130, 131). In Studies I and II, all qualitative comments were sorted into the 12 variables included in QUEST 2.0 (117), and one additional category emerged (lack of money).

Analysis of interview text

Content analysis can be applied to messages from individuals, such as responses to open-ended questions in interviews, or to messages from groups, for example focus group discussions. Qualitative content analysis is

an inductive process, generating general themes from core content (113), and takes the context of the data into account during analysis (132, 133). The first step of this analysis involves a qualitative review of the message of the data (130). The aim of the study and depth of data guided which type of content analysis was employed (i.e. manifest or latent) and the most appropriate coding scheme (132). Manifest content analysis is descriptive, and the elements are clearly present in the analysed texts (130, 132, 133). Latent content analysis includes analyses of the underlying meaning of the texts (132).

Interviews in Studies III and IV were listened to several times in order to capture the content. The text, which was transcribed verbatim, was then divided into meaning units. Each meaning unit was condensed on a descriptive level, staying close to the original text for Study IV and condensed at a more interpretive level in Study III. The condensed meaning unit was then abstracted with a code. These codes were then grouped, compared, and contrasted, resulting in the generation of a number of themes (Studies III and IV). The trustworthiness of data and analysis needed to be reassessed during the analytical process (132). For Study III, a second round of interviews was conducted after the preliminary content analysis, in order to ensure the credibility of the study and to improve the depth of the collected data in terms of the themes which emerged during the preliminary content analysis. Steps were discussed by the authors, and codes, categories, and themes (Studies III and IV) were refined in order to reach the final result. During the content analysis, both pre-understanding and background shape interpretation, which is particularly important when the data is not collected from within the researcher's own culture (113).

Finally, a comparative analysis of the results of Studies III and IV was conducted in this thesis. The analytical approach used was concept analysis, where findings from the different studies were used. Studies III and IV had similar research designs and involved the recruitment of two groups of professionals with differing education levels; prosthetic/orthotic technicians in Sierra Leone and prosthetists/orthotists in Pakistan. Similar procedures for interviewing and analysing the qualitative data were used in both studies,

although the abstraction level was higher in Study III. Comparisons and synthesis of results in Studies III and IV generated new themes common to both Sierra Leone and Pakistan, as well as unique themes for each country.

Ethical considerations

The studies in this thesis have been conducted in compliance with ethical principles regarding human clinical research (134, 135). This refers to the principle of respect for persons, including respect for autonomy, the principle of beneficence and non-maleficence, and the principle of justice (135, 136). The work in this thesis focuses on people with disabilities in need of assistive devices in poor settings and staff providing prosthetic and orthotic services in so-called developing countries. Efforts have been made to apply these ethical principles throughout the studies so as to overcome the challenges that arise during international research with diverse populations in regards to culture, economic status, and level of education (135, 137). It was the author's intention that the content of this research reflect a profound respect for those who struggle with poverty and disability.

The studies were conducted in collaboration with non-governmental organisations, the Ministry of Health and Sanitation in both Malawi and Sierra Leone, and a university in Pakistan. International and national standards within each country at the time of each study regarding research ethics were considered. However, the development of national guidelines for research ethics varied across the three countries included in this thesis. Ethical approval was obtained from the National Research Council of Malawi (138) (Study I), the National Scientific Ethical Review Committee in Sierra Leone (139) (Study II), Handicap International/New Steps Mercy Ships and Prosthetic Outreach Foundation in Sierra Leone (Study III), and the Pakistan Institute of Prosthetics and Orthotics (Study IV).

Furthermore, Study II, conducted in Sierra Leone, was also approved by Handicap International and the National Rehabilitation Centre, Freetown, the Prosthetic Outreach Foundation in Makeni, and the Ministry of Health and Sanitation, which is responsible for rehabilitation and disability. The

managers of the four rehabilitation centres were informed about the study and gave their approval to both access patient registers from their centre and conduct the study. Cultural considerations were made and, in rural settings, it was necessary to obtain permission from community leaders (135). The rehabilitation centre in Bo provided outreach services at Koribondo town, and Giama Bongoo Chiefdom, and the town chief gave permission to move freely in his chiefdom and meet participants for the study. In Sandor, chiefdom permission was given from the health centre within the chiefdom. The results of the studies have been published, and have been or will be reported back to the partners in each country.

The principle of respect for a person's autonomy, and particularly of respect for persons with impaired autonomy, was applied, and every participant was free to decide if they wanted to take part (135). Participants were informed about the studies, and both oral and written informed consent was obtained. For Studies III and IV, all participants understood English well, and information about the studies was given in English. In Studies I and II, the participants were prosthetic and orthotic patients with physical disabilities, and had the cognitive ability to make their own choice as to whether or not to participate. Information about the study was provided in English and local languages. Some of the patients were illiterate, and in these cases the information was read to them in their own language by local research assistants. Understanding of the concepts of informed consent varied. In order to ensure that the informed consent process was conducted in an ethical manner, the local research assistants and interpreters were educated on principles for informed consent before data collection began. To this end, the WHO teaching material on informed consent and confidentiality for capacity building within research ethics for developing countries was used. Concepts were explained simply, and examples were given (136).

The principle of beneficence and non-maleficence (135) refers to the obligation to maximize benefit and minimize harm. The principle of non-maleficence (135, 136) was applied by educating research assistants and interpreters on what informed consent, autonomy, and confidentiality means,

and discussing this with them before the data collection started. Personal data connected to participants was treated with confidentiality.

It has been recommended by the Council for International Organisations of Medical Sciences (CIOMS) that travel costs and other expenses incurred while taking part in a study should be covered by the researchers (135). Research ethics guidelines also state that participants may receive free rehabilitation services; participants who receive no direct benefit from research may also be compensated for their time. The rehabilitation services offered or the compensation for participating in a study should not, however, be so large or extensive that it may lead to prospective participants giving consent on the basis of the compensation provided and/or against their better judgment (135). In Studies I and II, all patients who travelled to any of the rehabilitation centres to participate were compensated for costs associated with using public transport. In Study I, where data was collected at the prosthetic and orthotic centre in Malawi, the participants were offered the opportunity to see their prosthetist/orthotist after participating in the study. Many participants needed repairs for their assistive device, and did not have the resources to pay for travel to the centre for repairs and follow-up services. These individuals took the opportunity to have their assistive devices repaired after participating in the study. Participants who travelled long distances and required an overnight stay to have their devices repaired were offered free accommodation at the hospital by the prosthetic and orthotic centre in Lilongwe, Malawi. In Study II in Sierra Leone, where most of the data was collected in patients' homes or work places, participants were given a small amount of money, sufficient to cover the cost of eating for a day.

The principle of justice (135, 136) requires that one considers if the benefits and burdens of participation in research are fairly distributed. In 2002, The CIOMS guidelines for biomedical research defined vulnerable persons as those without the ability to protect their own interests, who lack the capacity to give informed consent, or do not have alternative means of obtaining rehabilitation. In order to avoid violations of vulnerable participants, special consideration and sensibility is required. Many of the persons with a

disability who were included in Studies I and II can be considered to be vulnerable, but all of them had the cognitive ability to make their own choice as to whether to participate. All of the persons with disabilities who were asked to participate had received rehabilitation services between April 2009 and November 2010. The principle of justice also requires that research should be responsive to the needs of vulnerable people within the area of research and, as far as possible, leave the population in a better position to obtain rehabilitation and protect its own health (135). CIOMS guidelines (135) also state that researchers should not take advantage of the relative inability of developing countries to protect their interests by conducting research intended for the market or for healthcare in high income countries. The aims of the studies presented in this thesis relate to patients using low-cost prosthetic and orthotic devices and the education of professionals working in developing countries. The study population can potentially benefit from the results of these studies.

Results

The results of Studies I and II, along with the comparisons between the studies, are presented. This is followed by the results of regression analysis, using the combined data sets of Studies I and II. The last section presents the combined result of Studies III and IV.

Results (Studies I and II)

Causes of disability, use, and condition of assistive devices

Two hundred and twenty-two patients participated in Studies I and II; 143 (64%) were prosthetic users and 79 (36%) were orthotic users. In Malawi there were 18 (22%) orthotic patients, compared with 60 (43%) in Sierra Leone ($p < 0.001$). In Malawi, there were more below-knee assistive device users [44 (53%) compared to 49 (35%) in Sierra Leone, $p = 0.009$; Table 5]. The most common causes of impairments in Malawi were traffic accidents, non-healing wounds, and fractures, while in Sierra Leone, violence and polio were the most common causes. The majority of prosthetic and orthotic devices were in use by patients; 74 (90%) in Malawi and 118 (86%) in Sierra Leone, although in both countries about half of the assistive devices that were in use needed repairs. Patients used their prosthesis or orthosis an average of nine hours a day in both Malawi and Sierra Leone. There were less male patients included in the Malawian study as compared to the study in Sierra Leone [47 (57%) in Malawi and 100 (72%) in Sierra Leone, $p = 0.02$].

The majority of patients had no spare prosthetic or orthotic device; 75 (90%) in Malawi and 123 (89%) in Sierra Leone. Ten (12%) patients in Malawi, compared to 55 (41%) in Sierra Leone, preferred to use crutches rather than a prosthetic or orthotic device. Thirty-five (42%) patients in Malawi and 48 (35%) in Sierra Leone used crutches along with their device, while thirty-eight (46%) in Malawi and 32 (24%) in Sierra Leone did not use crutches at all. Ownership and use of wheelchairs, either instead of or along with

devices, was significantly less common in Malawi than in Sierra Leone [5 (6%) as compared to 28 (20%), ($p=0.004$)].

Patients' mobility when walking with their assistive device

Use of assistive devices was found to improve the ability of patients to walk in both Malawi and Sierra Leone. Approximately one third of patients were not able to walk at all without their assistive device [40 (48%) in Malawi and 30 (22%) in Sierra Leone]. The majority of patients could walk more than one kilometre when using their prosthetic or orthotic device [49 (59%) in Malawi and 101 (73%) in Sierra Leone]; however, only a third could manage this distance without using their prosthesis or orthosis. In Malawi, 17 (21%) patients could manage to move 100 metres or more without their prosthesis or orthosis, in comparison to 76 (55%) in Sierra Leone ($p < 0.001$). In Malawi, 20 patients (24%) reported that they could not walk at all, or could walk a few metres, with their assistive device, in comparison to only 12 (9%) in Sierra Leone ($p=0.002$).

The majority of patients had the ability to rise from a chair and move around in their home without difficulties. More than half of the patients experienced difficulties or could not walk at all on uneven ground, up and down hills, and on stairs. Compared to patients in Malawi, a higher percentage of patients in Sierra Leone could not, or had difficulties, walking on uneven ground ($p < 0.001$). About half of patients had the ability to travel by car or by bus without difficulty (Table 8). Furthermore, about half of the patients reported that they did not have, or sometimes did not have, the possibility of accessing prosthetic and orthotic workshops or rehabilitation services due to distance, costs, availability of transport, or lack of personal assistance [59 (71%) in Malawi and 55 (40%) in Sierra Leone].

Table 8: Mobility in prosthetic and orthotic users

	Patients, Malawi n=83 (%)	Patients, Sierra Leone n=139 (%)
Ability to rise from a chair, n =220		
Yes, without any difficulty	64 (77)	97 (71)
Yes, with difficulty, or No, not at all	19 (23)	40 (29)
Ability to move around in the home, n=216		
Yes, without any difficulty	65 (80)	108 (79)
Yes, with difficulty, or No, not at all	15 (19)	28 (21)
Not applicable	1 (1)	
Ability to walk on uneven ground/roads, n=218		
Yes, without any difficulty	48 (59)	46 (34)
Yes, with difficulty, or No, not at all	34 (41)	90 (65)
Not applicable		1 (1)
Ability to walk up and down a hill, n=212		
Yes, without any difficulty	17 (21)	31 (23)
Yes, with difficulty, or No, not at all	62 (78)	102 (75)
Not applicable	1 (1)	3 (2)
Ability to walk on stairs, n=212		
Yes, without any difficulty	30 (38)	45 (33)
Yes, with difficulty, or No, not at all	47(60)	90 (66)
Not applicable	2(3)	1(1)
Ability to get in and out of a car , n=211		
Yes, without any difficulty	45 (56)	70 (52)
Yes, with difficulty, or No, not at all	34 (43)	65 (48)
Not applicable	1(1)	
Ability to and get on and off a bus, n=206		
Yes, without any difficulty	44 (56)	62 (46)
Yes, with difficulty, or No, not at all	34 (43)	66 (49)
Not applicable	1 (1)	7 (5)

The table is adapted from Papers I and II.

Pain and wounds related to use of assistive device

Approximately one third of patients ‘always or often’ experienced pain related to use of their device [33 (40%) in Malawi and 46 (34%) in Sierra Leone], and only a few patients’ reported that they never experienced pain related to use of their device [6 (7%) in Malawi and 12 (9%) in Sierra Leone]. Wounds or skin irritations related to use of prosthetic or orthotic devices were experienced ‘always or often’ by 22 patients (27%) in Malawi and 37 (27%) in Sierra Leone. Only one quarter of the patients ‘never’ experienced wounds or skin irritations [21 (25%) in Malawi and 30 (22%) Sierra Leone].

Patient satisfaction with assistive device and service delivery

The results of QUEST showed that patients were quite satisfied with their assistive device, and also quite or very satisfied with the services received. Patients in Malawi were significantly more satisfied with service delivery than in Sierra Leone ($p < 0.001$); Table 9. Comfort, dimensions, and security with assistive device were the items which received the lowest satisfaction scores (mean scores 3.5-3.7 in Malawi and Sierra Leone).

Table 9: Results of patients' level of satisfaction of assistive device and service

Scale (1-5)	Malawi		Sierra Leone	
	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)
Satisfaction of Assistive Device, total score	3.9 (.7)	4.0 (1.0)	3.7 (.8)	3.8 (1.1)
Satisfaction of Services, total score	4.4* (.7)	4.7 (1.0)	3.7* (1.0)	4.0 (1.8)

Response scale: 1) Not satisfied at all; 2) Not very satisfied; 3) More or less satisfied; 4) Quite satisfied; 5) Very satisfied (117). *T test $p < 0.001$

In both countries, patients reported high levels of satisfaction regarding training received, coordination between professionals, and ease of keeping their assistive device clean. However, patients in Malawi were significantly more satisfied with the cosmetic appearance of their device than patients in Sierra Leone (mean score 4.4 in Malawi and 3.5 in Sierra Leone, $p < 0.001$).

About half of all patients reported that they did not have the ability to pay for costs associated with receiving prosthetic and orthotic services, including accommodation and travel to rehabilitation centres [66 (82%) in Malawi and 66 (45%) Sierra Leone, ($p < 0.001$)]. Furthermore, the majority of patients indicated that staff gave them the opportunity to express their views about the device [48 (59%) in Malawi and 108 (80%) Sierra Leone, $p < 0.001$]. Eighty-two percent trusted and had confidence that their prosthetist/orthotist was capable of delivering a quality service; Table 10.

Table 10: Patients' views about service delivery

	Patient, Malawi n=83 (%)	Patient, Sierra Leone n=139 (%)
Ability to pay for costs associated with receiving the service appliances, accommodation, travel n=222		
Yes	15 (18)	76 (55)
No	68 (82)	63 (45)
The prosthetist/orthotist or technician gives me the opportunity to express my views about my assistive device n=216		
Completely true	48 (59)	108 (80)
Sometimes true	15 (19)	20 (15)
Completely false	18 (22)	7 (5)
I trust and have confidence that my prosthetist/orthotist is capable of delivering a quality service n=221		
Completely true	68 (82)	115 (83)
Sometimes true	11 (13)	18 (13)
Completely false	4 (5)	5 (4)

Patients were asked to choose what they considered to be the three most important items among the 12 included in QUEST. The patients in Malawi and Sierra Leone reported that access to repairs and servicing of their assistive device were most important, followed by provision of follow-up services and durability of the device. In Sierra Leone, comfort was scored as one of the three most important items (see Table V in Paper I and Table V in Paper II).

Manifest content analysis was performed on 1304 comments (418 comments in Malawi in Study I and 886 comments in Sierra Leone in Study II) related to problems experienced with assistive devices and service delivery. The main problems in Malawi were related to lack of comfort and pain when using the assistive device (99 comments by 62 respondents), limitations in the effectiveness of the assistive device (55 comments by 45 respondents), and problems related to poor dimensioning of the assistive device (41 comments by 40 respondents). The main concerns in Sierra Leone were also related to lack of comfort and pain experienced when using the assistive device (148 comments by 78 respondents), and problems related specifically to service delivery, including the fact that the patients could not cover related

expenses (145 comments by 94 respondents) and felt that there were limitations to the effectiveness of their assistive device (107 comments by 69 respondents).

Sub-group comparisons within Malawi and Sierra Leone

The main results of the sub-group comparisons are presented below. Complete results are presented in the articles.

Type of assistive device

In both Malawi and Sierra Leone, orthotic patients reported significantly more difficulty in walking and moving around in their home than prosthetic users. In Sierra Leone, the orthotic group reported significantly more difficulties or lack of ability to use cars and buses and were also significantly less satisfied with the service provided than prosthetic patients. Forty-eight percent of orthotic patients had no income at all, compared to 27% of prosthetic patients. Orthotic patients also had fewer opportunities to access services (Studies I and II).

Level of assistive device

Patients with above-knee assistive devices had more difficulties in walking and moving around than those with below-knee devices. In both Sierra Leone and Malawi, a higher proportion of patients with above-knee devices had difficulties or were unable to walk on stairs when compared to patients with below-knee devices. In Sierra Leone, patients using above-knee devices reported more difficulties or were unable to rise from a chair, move around their home, walk up and down hills, and use cars or buses than patients using below-knee assistive devices. In Malawi, patients with above-knee devices reported significantly more wounds and skin irritations than users of below-knee devices. Only in Sierra Leone were patients with above-knee assistive devices less satisfied with their device. In both Malawi and Sierra Leone, patients using above-knee assistive devices were less satisfied with the services received than patients with below-knee assistive devices. It was more common that above-knee assistive devices were not used because they were completely broken in Sierra Leone. In Malawi, patients using below-knee assistive devices walked without crutches more often than patients with

above-knee assistive devices. Forty-five percent of patients using above-knee assistive devices had no income, compared to 19% of those using below-knee assistive devices in Sierra Leone.

Demographic aspects related to assistive device and service

Regarding sex, statistically significant differences were only found in Sierra Leone. Females reported fewer possibilities for accessing workshops than males. Thirty-four percent of females and 5% of males had no access to services, while 11% of females and 34% of males had infrequent access. It was more common for females to experience general difficulties, and many struggled with moving around their home, walking on uneven ground and on hills; on the whole, women were less satisfied with their device than males (Study II). Patients living in rural Malawi and Sierra Leone were more frequently unable to cover costs associated with receiving the service and appliances than those living in urban areas. In Malawi, patients living in urban areas had significantly more difficulties than patients living in rural areas when walking on uneven ground. In Sierra Leone, patients living in rural areas reported fewer opportunities to access services than patients in living in urban areas, and patients in rural areas were also less satisfied with the coordination between prosthetic and orthotic services and other rehabilitation professionals such as physiotherapists, community-based rehabilitation workers, and physicians, than patients living in urban areas (Studies I and II).

Significant differences related to level of income were only observed in Sierra Leone. Patients with a regular income used their assistive devices longer per day (average 11 hours) than patients with a more sporadic income (average 9 hours) or none at all (average 7 hours). Patients with no income and those with a regular income reported that their assistive device caused them pain more frequently than those who sometimes had an income. Patients with no income were younger (average age 28 years) than those with occasional (average age 39 years) or regular income (average age 37 years) (Study II).

Similarities and differences in results from Malawi and Sierra Leone

A summary of similarities and differences concerning patients' mobility and satisfaction with their lower-limb prosthetic or orthotic device and related service delivery is presented in Table 11.

Table II: Summary of similar patterns and differences in Malawi and Sierra Leone

	Similarities	Differences
Cause, use and condition	<p>The majority of prosthetic and orthotic devices were in use by patients.</p> <p>About half of the assistive devices that were in use needed repairs.</p>	<p>Use of crutches or wheelchairs, instead of or together with devices, was less common in Malawi than in Sierra Leone.</p>
Mobility	<p>The majority of patients had the ability to move around in their home without difficulty.</p> <p>Slightly more than half of the patients experienced difficulties or could not walk at all on uneven ground, up and down hills, and on stairs.</p> <p>The majority of patients had the ability to travel by car or by bus, although about half experienced difficulties while performing these activities.</p> <p>Orthotic patients reported significantly more difficulties walking and moving around in their home than prosthetic patients.</p> <p>Patients using above-knee devices had more difficulties than those using below-knee devices when walking on stairs.</p>	<p>In Malawi, significantly fewer patients could manage to move 100 metres or more without their prosthesis or orthosis than in Sierra Leone.</p> <p>Patients in Malawi had less difficulty walking on uneven ground than patients in Sierra Leone.</p> <p>In Sierra Leone, females experienced more difficulties in walking.</p>
Pain	<p>Lack of comfort and pain while using the assistive device was reported, and also confirmed in qualitative comments as a major problem.</p>	
Prosthetic or orthotic devices	<p>Patients reported being quite satisfied with prosthetic or orthotic devices.</p> <p>Comfort, dimensions, and security with assistive device were the items which received the lowest satisfaction scores.</p>	<p>Patients in Malawi were more satisfied with the cosmetic appearance of devices than patients in Sierra Leone.</p> <p>In Sierra Leone, females were less satisfied with their device.</p>
Service	<p>Repairs/servicing, follow-up service, and durability were rated as the three most important items included in QUEST.</p> <p>Patients living in rural areas had significantly less ability to pay for the costs associated with receiving service and devices than patients living in urban areas.</p>	<p>Patients in Malawi were more satisfied with service delivery than patients in Sierra Leone, this was confirmed in qualitative comments.</p> <p>Patients in Malawi indicated that staff gave them few opportunities to express their views about the device, in contrast to findings from Sierra Leone.</p> <p>In Sierra Leone, females reported fewer possibilities to access workshops than males.</p>

Variables associated with satisfaction of assistive devices and services

In order to identify the variables associated with satisfaction of assistive device and service in the combined data set (Studies I and II), simple linear regression analyses of 23 initial variables was conducted. Sixteen variables demonstrated a significant association with satisfaction of device ($p < 0.1$), while 15 demonstrated a significant association with satisfaction of service ($p < 0.1$); Table 12.

The variables which were selected for the final multiple regression models were identified through multiple regression analysis with backward elimination ($p < 0.1$). The variables which were significantly associated ($p < 0.1$) to satisfaction of assistive device were; pain, general condition of the device, ability to walk on uneven ground/roads, ability to walk on stairs, and ability to get in and out of a car. The variables which were significantly associated ($p < 0.1$) with satisfaction of service were; country, general condition of the device, ability to walk on uneven ground, ability to pay for costs associated with receiving the service appliances, accommodation, travel, and ability to walk on stairs; Table 13.

Table 12: Variables included in regression analysis

Independent variables included in simple regression analysis	Combined data	
	Satisfacti on of assistive device p- value	Satisfacti on of service p-value
Country (Malawi; Sierra Leone)	.291	<.001*
Sex (Female; Male)	.477	.786
Age	.617	.644
Rural/urban areas (Living in cities; Living in villages)	.642	.425
Level of income (No income at all; Regular income from employment)	.295	.994
(No income at all; Sometimes income)	.629	.456
Ability to pay for costs associated with receiving the services	<.001*	.058*
Type of assistive device (Prosthesis; Orthosis)	.132	<.001*
Level of assistive device (Below-knee assistive devices; Above-knee assistive devices)	.008*	<.001*
General condition of device (In use good condition; Broken, cannot be used)	.001*	<.001*
(In use but needs repair; Broken, cannot be used)	.371*	.002*
Hours assistive device is used per day	<.001*	.005*
Use of crutches (Yes, instead of device and Yes, together with device; No)	.001*	.001*
Use of wheelchair (Yes, instead of device and Yes together with device; No)	.404	.058*
Walking distance without assistive device (Not at all, 0 meters and a few meters; About 100 meters and about a kilometre or more)	.589	.051*
Walking distance with assistive device (Not at all, 0 meters and a few meters; About 100 meters and about a kilometre or more)	.002*	.633
Ability to rise from a chair (Yes, without any difficulty; Yes, with difficulty and No, not at all)	.001*	.058*
Ability to move around the home (Yes, without any difficulty; Yes, with difficulty and No, not at all)	<.001*	<.001*
Ability to walk on uneven ground/roads (Yes, without any difficulty; Yes, with difficulty and No, not at all)	<.001*	<.001*
Ability to walk up and down a hill (Yes, without any difficulty; Yes, with difficulty and No, not at all)	<.001*	.118
Ability to walk on stairs (Yes, without any difficulty; Yes, with difficulty and No, not at all)	<.001*	<.001*
Ability to get in and out of a car (Yes, without any difficulty; Yes, with difficulty and No, not at all)	<.001*	<.001*
Ability to and get on and off a bus (Yes, without any difficulty; Yes, with difficulty and No, not at all)	<.001*	<.001*
Assistive device causes pain (Always and Often; Seldom and Never)	<.001*	.631
Assistive device causes wounds/skin irritations (Always and Often; Seldom and Never)	<.001*	.155

*Variables showing a significant association with the dependent variables in simple regression analysis $p < 0.10$ were entered into the multiple regression analysis.

Table 13: Variables associated with QUEST total score for satisfaction of assistive device and service

Combined dataset			
Variables	B	95% CI	P-value
Model: Satisfaction of assistive device*			
Constant/Intercept	2.92	2.61 to 3.23	
Pain [Seldom Never (1); Always Often (0)]	.37	.20 to .54	<.001
General condition of device			
[In use good condition (1); Broken, cannot be used (0)]	.54	.24 to .84	<.001
[In use but needs repair (1); Broken, cannot be used (0)]	.15	-.14 to .45	.308
Ability to walk on uneven ground/roads			
[Yes, without difficulty (1); Yes, with difficulty and No, not at all (0)]	.35	.18 to .52	<.001
Ability to walk on stairs			
[Yes, without any difficulty (1); Yes, with difficulty and No, not at all (0)]	.23	.03 to .42	.023
Ability to get in and out of a car			
[Yes, without difficulties (1); Yes, with difficulty and No, not at all (0)]	.20	.01 to .39	.038
Model: Satisfaction of service**			
Constant/Intercept	3.33	2.92 to 3.74	
Country [Malawi (1); Sierra Leone (0)]	.63	.38 to .88	<.001
General condition of device			
[In use good condition (1);Never used and Broken, cannot be used (0)]	.86	.46 to 1.26	<.001
[In use but needs repair (1); Never used and Broken, cannot be used (0)]	.35	-.04 to .74	.077
Ability to walk on uneven ground/roads			
[Yes, without difficulty (1); Yes, with difficulty and No, not at all (0)]	.56	.36 to .79	<.001
Ability to pay for costs associated with receiving the service appliances, accommodation and travel			
[Yes (1); No (0)]	.40	.17 to .64	.001
Ability to walk on stairs			
[Yes, without any difficulty (1); Yes, with difficulty and No, not at all (0)]	.34	.11 to .37	.004

*Satisfaction of assistive device: Adjusted R²= 30%, F-ratio=15

**Satisfaction of service: Adjusted R²= 38%, F-ratio=21

Results (Studies III and IV)

Besides patient-reported outcomes, this thesis also focused on professionals' experiences of service delivery and their views of the education they received as preparation for providing a high quality service. A second ordered concept analysis of themes for prosthetic and orthotic service delivery and education for Studies III and IV is presented below. The sub-themes in Table 14 and 15 are themes in Studies III and IV.

Prosthetic and orthotic service

The three common themes in Sierra Leone and Pakistan regarding service delivery were: 1) Low awareness and prioritisation of prosthetic and orthotic services; 2) Difficulty managing specific pathological conditions and problems with materials; 3) The need for further education and desire for professional development. Two further themes were found to be unique to Sierra Leone: 1) People with disabilities have low social status; 2) Limited access to prosthetic and orthotic services. The themes are presented in Table 14, and summarised below.

Table 14: Common and unique themes in Sierra Leone and Pakistan of prosthetic and orthotic service delivery.

Themes	Sub-themes from Sierra Leone	Sub-themes from Pakistan
Themes common to Sierra Leone and Pakistan		
Low awareness and prioritising of prosthetic and orthotic services.	Low priority on the part of government.	Low awareness of prosthetic and orthotic services.
Difficulty managing specific pathological conditions and problems with materials.	Problems with materials and machines.	Management of specific pathological conditions and administrative duties are most difficult for graduates.
The need for further education and desire for professional development.	*Desire for professional development	Currently varied opportunities for professional development Well-functioning support from senior staff. Prosthetists/Orthotists would like to specialise. A desire for networking within the country and interaction from outside.
Themes unique to Sierra Leone		
People with disabilities have low social status in Sierra Leone.	Low public awareness concerning disabilities. Patients neglected by family. Marginalisation in society	
Limited access to prosthetic and orthotic services available.	Limited access to the prosthetic and orthotic services available. Appraisals of work satisfaction and norms.	

*The content of the sub-theme 'desire for professional development' in Study III is divided into two new themes in Table 15.

Prosthetic and orthotic service delivery – Themes common to Sierra Leone and Pakistan

Low awareness and prioritising of prosthetic and orthotic services

The prosthetic and orthotic professionals who participated in Studies III and IV perceived that other healthcare professionals and the general population had poor knowledge about rehabilitation and prosthetic and orthotic service delivery in both Sierra Leone and Pakistan. There was also a low awareness regarding what services the prosthetic and orthotic workshops could offer, especially in rural areas. They called for increased dissemination of information regarding services available through referral systems, an increase in the availability of community-based rehabilitation workers who could reach rural areas in Sierra Leone, as well as seminars for health professionals in Pakistan.

In Sierra Leone, participants expressed distrust of the government's ability to independently sustain rehabilitation services that fully support poorer people. The participants doubted that the government could provide funding for appropriate material, staff with appropriate skills to run the rehabilitation centres, or the capacity to empower people with disabilities. Concerns were also raised regarding charges imposed upon patients for the provision of prosthetic and orthotic devices, low salaries for staff, and the low level of transparency offered by the management of rehabilitation centres. The government had taken over parts of the services 2009, but participants expressed the view that non-governmental organisations were needed to provide financial support, materials, and assistance (*Low priority on the part of the government, Study III*).

In Pakistan, surprisingly, few prosthetist/orthotist positions were available in government hospitals. It appears that these institutions mainly employ personnel with no formal education, and participants felt that there should be at least one trained prosthetist/orthotist at every hospital which provides prosthetic and orthotic services (*Low awareness of prosthetic and orthotic services, Study IV*).

Difficulty managing specific pathological conditions and problems with materials

An urgent need for materials and financial support for the purchase of materials was emphasised by participants in Sierra Leone. Participants in Pakistan reported difficulties managing specific pathological conditions, and problems with administration related to patient management and the production of assistive devices.

Participants were not satisfied with the quality of local materials for fabricating prosthetic and orthotic devices. It was perceived that there was a need for more adequate machinery and increased availability of electricity in order to provide a high-quality service. They expressed that ICRC polypropylene technology worked well (*Problems with materials and machines, Study III*).

In Pakistan, participants felt well-prepared for providing appliances to polio patients and below-knee amputees. Major concerns were, however, expressed in relation to the management of other pathological conditions, including cerebral palsy, upper-limb conditions, spinal injuries, diabetic patients, and above-knee amputees. Participants also indicated that they were weak at evaluating patient outcomes after fitting devices (*Management of specific pathological conditions and administrative duties are most difficult for graduates, Study IV*).

The need for further education and desire for professional development

In Sierra Leone, the participants perceived a need for professional development concerning elementary prosthetic and orthotic theory. In Pakistan, participants would like to specialise so as to provide quality services to specific groups of patients, and desired the opportunity to work towards higher degrees to be able to both improve services in Pakistan and work abroad. Support from senior staff was appreciated, and functioned well in both countries.

In Sierra Leone, participants were satisfied with the on-the-job training that they had received from international prosthetic and orthotic experts and local professionals. Despite this, there was a desire for further education and professional development related to prosthetic and orthotic design and theory. The justification for the need of further education was related to recognition of the profession and improved patient satisfaction. The few prosthetists/orthotists with university-level education shared their knowledge and ideas on how to produce assistive devices in Sierra Leone (*Desire for professional development, Study III*).

In Pakistan, the newly qualified graduates indicated that they received good support and guidance from senior staff when entering the workforce. Senior colleagues had been supportive via telephone to those graduates working where no senior staff were available, but participants expressed a desire to have someone to work alongside. Most of the participants said that they were willing to train others if required (*Well-functioning support from senior staff, Study IV*).

There was a desire among participants in Pakistan to specialise in specific areas, including gait biomechanics, new technologies, orthotics for cerebral palsy and polio, upper-limb prosthetics, spinal orthotics, research, and management (*Prosthetists/Orthotists would like to specialise, Study IV*).

Participants would like to see increased opportunities for international collaborations between teachers to facilitate the exchange of ideas and increased communication. They also would like a network between prosthetists/orthotists working in Pakistan (*A desire for networking within the country and interaction from outside, Study IV*).

In Pakistan, some participants had no opportunities at all for professional development, while some had participated in short courses. One had participated in an upgrade course, providing them with a Bachelor-level education. Almost all participants said they would like to complete a Bachelor's or Master's degree that was only available abroad, so as to improve the prosthetic and orthotic services within Pakistan. Some of the

male participants wanted to work abroad and earn more money, while the females expressed a desire to return to PIPOS and improve the school and supply the skills and knowledge that are currently lacking (*Currently varied opportunities for professional development, Study IV*).

Prosthetic and orthotic service delivery - Themes unique to Sierra Leone

People with disabilities have low social status in Sierra Leone

The local prosthetic/orthotic technicians in Sierra Leone stated that understanding of the underlying causes of disability was very poor among the general public and in families who had relatives with a disability. Traditional beliefs tended to underpin the general community's understanding of the cause of disability. For example, polio was considered to be a result of witchcraft, to stem from evil or the will of God, and a disabled child was considered to be punishment for the bad behaviour of parents. Persons with disabilities were described as living in poverty and having very limited opportunities in society. They expressed concerns that persons with disabilities did not have access to the services that they deserve. Besides polio, leprosy was also commonly seen as being a result of witchcraft, while amputations are seen in relation to war or accidents. Traditional beliefs were seen as a barrier that often delayed the seeking of medical care in favour of traditional treatments. Participants reported low societal acceptance of deformities, especially in rural areas. It was perceived that education regarding the underlying cause of disability could help to increase acceptance of the fact that disability is a medical problem. Assistive devices were seen as giving patients the opportunity to contribute productively to society, but participants also perceived that patients were ashamed of using appliances (*Low public awareness concerning disabilities, Study III*).

Participants indicated that the majority of disabled children who had been abandoned by their family and were begging on the streets were held in low esteem by people in their village, and were sometimes living in dangerous situations. This was considered to be the case due to traditional beliefs about

disabilities and, because they could not contribute to the household, families often did not want to maintain contact with a disabled family member. The neglect of persons with disabilities by their families also complicated the provision of rehabilitation services. Participants expressed the opinion that education of the extended family of persons with disabilities could contribute to changing attitudes. They perceived that families were in need of increased knowledge about disability and support in order to be able to take care of their disabled family member (*Patients neglected by family, Study III*).

In general society, people with disabilities were held in low esteem, being seen as not useful or evil. Men with disabilities had a higher status than women with disabilities. Amputees were held in higher esteem than people with polio. Polio patients were described as having very limited opportunities to use public transport or gain employment. Participants thought that people with disabilities would appreciate assistance in improving their living conditions and the function of their devices in order to increase mobility. They expressed that people with disabilities should have the right to access schools and employment in order to be able to leave the streets and live in a house. Skills training for persons with disabilities were also suggested in order to reduce poverty and increase access to services. Participants felt empathy for people with disabilities, and expressed concern that such people were not protected by the law. Participants found that poverty was a hindrance when supporting people with disabilities (*Marginalisation in society, Study III*).

Limited access to the prosthetic and orthotic services available

Participants reported problems experienced by patients in accessing rehabilitation services. This related mainly to patients living in the provinces, but also to some who lived locally and could not afford transport to the centres. Access was also limited by hidden fees that poor patients could not afford, as some staff requested extra money from patients in order to receive services. Reasons related to the inability of patients to access services were; no available vehicle, and motorbikes that patients were not capable of riding. Women were often dependent on their husbands when it came to funding for transport, and therefore had less access to services than

men. The participants were satisfied when accommodation could be provided for patients travelling long distances to the rehabilitation centres. Participants reported that they were hesitant to initiate fabrication of a device for someone from far away, as they might not be able to come back for a delivery appointment. Outreach services and follow-up programmes were suggested by some of the participants as a means of providing access to services for rural patients. Other participants were especially dissatisfied regarding the quality of prosthetic and orthotic services delivered by outreach, and the limited possibilities for following up with their patients (*Limited access to the prosthetic and orthotic services available, Study III*).

The participants indicated that helping patients walk gave them joy and a deep sense of meaning. Participants who possessed a personal experience of disability felt empathy for their patients, and were highly motivated to provide the best possible service. However, they also mentioned that services were distributed unequally between different target groups. Furthermore, it was reported that there had been difficulties with regard to unprofessional behaviour amongst staff towards patients. A low level of transparency in respect to costs and payment for rehabilitation services and appliances was of concern. It was emphasised that patients were dependent on appliances to be able to move, that some patients could no longer access services because these were no longer free of charge, and that not everyone could afford to pay even a small fee (*Appraisals of work satisfaction and norms, Study III*).

Prosthetic and orthotic education

The one common theme in Sierra Leone and Pakistan was a desire for improvements in prosthetic and orthotic education; Table 15.

Table 15: Themes common to Sierra Leone and Pakistan of prosthetic education

Themes common to Sierra Leone and Pakistan	Sub-theme from Sierra Leone	Sub-themes from Pakistan
Desired improvements in prosthetic and orthotic education.	*Desire for professional development.	Alter and improve programme content. Females experience inequality, but support from PIPOS management. Improve teachers' knowledge and vary the pedagogical approach. Outdated literature and no internet access.

*The content of the sub-theme desire for professional development in Study III is divided into two new themes in Table 14.

Prosthetic and orthotic education - Theme common to Sierra Leone and Pakistan

Sierra Leone had no local capacity to train staff at a university level, and so prospective students had to be sent to Tanzania to receive formal education. In Pakistan, the participants would like to see specific changes in the educational curricula, and equal treatment for females and males throughout education.

Desired improvements in prosthetic and orthotic education

The participants in Sierra Leone were worried about the future of their profession, pointing out that there was not enough trained staff to serve the country. Here, there was no female prosthetist/orthotist, and participants said that there was a need for female prosthetic/orthotic technicians (*Desire for professional development, Study III*).

Almost all of the participants in Pakistan mentioned that they would like to see specific changes to the educational curricula, particularly in reference to improvements in the content of biomechanics, psychology, anatomy, physiology, and pathology education. It was further suggested that too much time was spent on metalwork and mathematics. A desire for greater knowledge regarding the prescription of specific devices for cerebral palsy patients, and an ability to recognise when physiotherapy should be used instead of, or as a complement to, orthotic devices, was indicated. This suggested that the link between theoretical and practical teaching needs to be improved in the curricula, and that students would benefit from a multidisciplinary teaching environment (*Alter and improve programme content, Study IV*).

In Pakistan, participants reported that females were not treated equally, and were not given the same opportunities to learn as male students. In spite of the fact that PIPOS has been able to educate female clinicians, who are able to act as good examples for the female students, even though they do not feel that they are treated equally by all of the teachers. A number of male participants were of the opinion that the profession is only for men. However, some of the male participants agreed that both genders are needed within the profession, because female patients feel ashamed if a male prosthetist/orthotist takes a cast of them. One male respondent admitted that females are theoretically stronger and better at teaching, even though they are weaker when it comes to practical work (*Females experience inequality but support from PIPOS management, Study IV*).

The competency of teachers at PIPOS was addressed by a number of participants. The most urgent issues requiring attention were the staff's ability to teach biomechanics and their pedagogical attitude. Multiple participants stressed the need for a different approach with regard to more assignments, discussions, and varied examinations. Participants said that they would like to have more time to practice examination and consultation with patients during the internship, and to be involved in the prescription generation process. At present, it appears that interns are only assigned patients after a senior clinician has performed the examination and already

generated a prescription (*Improve teachers' knowledge and vary the pedagogic approach, Study IV*).

Available literature was outdated and insufficient in the PIPOS library, and at the workshops where participants were employed. The participants believed that it is important to be taught the 'older' conventional technology due to the economic situation in Pakistan, but were interested in increasing their awareness of modern technology. Neither teachers nor students had access to internet facilities or other online medical resources, and no research articles were used in the education programme (*Outdated literature and no internet access, Study IV*).

Discussion

The first part of this section consists of a discussion of the main findings of Studies I and II, and Studies III and IV. This is followed by a discussion of how prosthetic and orthotic services contribute to the implementation of the CRPD, and how these results are related to the ICF. The last part of the discussion is related to the methodologies used in this thesis.

Results discussion; Studies I and II

Access to services

Poverty affects access to prosthetic and orthotic services for persons with disabilities. The CRPD (Article 20) rules that states shall facilitate access to quality mobility aids and make them available at an affordable cost (5, 45). Roughly half of the orthotic patients and a third of the prosthetic patients who were interviewed for this thesis had no income at all. The majority of patients in Malawi and about half of the patients in Sierra Leone included in the studies struggled, or did not have the ability, to pay for transport and the costs associated with receiving services; these patients were entirely dependent on support from others. The results indicated that patients in both Malawi and Sierra Leone were limited in physically accessing services as described in the joint position paper for mobility aids (45), due to long distances and limited access to transport. Fuel was very expensive in both countries (around 2 US \$ per litre in Malawi and 1 US \$ in Sierra Leone at the time of writing (140) in relation to the level of income of the populations; see Table 1 (12). Previous studies from African countries have also confirmed that lack of transport and the inability of persons with disabilities living in rural areas to pay for transport reduced access to healthcare and rehabilitation (141). Services were not affordable for all patients, as many lived in poverty. A study which investigated the inclusion of vulnerable groups in health policy in Africa indicated that loss of lower-limb mobility and expensive transportation affects access to healthcare (46). Study I in this thesis showed that the majority of patients in Malawi

managed to access the centre when funding for public transport was provided.

Patients in both Malawi and Sierra Leone reported that access to repairs and servicing of their assistive device, along with the provision of follow-up services and the durability of the assistive device, were the most important issues which contributed to satisfaction with the assistive devices and services (Studies I and II). These results were consistent with findings from a qualitative study in Haiti, which involved interviewing amputees who received rehabilitation services and prosthesis. In the Haitian study, amputees who had received a prosthesis worried about the availability of long-term follow-up services (94). These patients were given a three or six month follow-up appointment, and were also told that they could return any time before this six month period if they had problems with their prosthesis. This was, however, poorly understood, as most participants who experienced pain or discomfort did not call for an earlier appointment (94). Check-ups and regular maintenance of prosthetic and orthotic devices increases the lifespan of devices, and it is cheaper to undertake minor repairs than to entirely replace the prosthesis/orthosis (84). In order to provide cost-effective programmes and deliver assistive devices and related services, funding needs to be allocated not only to new assistive devices, but also to follow-up services. In Sierra Leone, the general condition of the device was associated with level of satisfaction with assistive device and service. The studies in Malawi and Sierra Leone showed that about half of the devices in use by patients needed repairs, indicating that the current follow-up system, where patients were required to come back to the facility using their own means, was insufficient.

Certain groups of persons with disabilities, such as women and people living in rural areas, are known to face multiple disadvantages in society and have limited access to services (80). In the ICRC Vietnamese Special Fund for the Disabled database, which contains entries dating back to the inception of the service and now include the records of 27,000 individuals, only 15% were women (100). In the Malawi study, 43% of patients were female, and in the Sierra Leone study, 28% of patients were female. There were indications that

women in Malawi with disabilities had less access to assistive devices than men, (37), while those in Sierra Leone were less able to access public healthcare (68). The CRPD states that all persons with disability should have access to rehabilitation services, including women (Article 6) and those in rural areas (Article 26) (5). The results from Sierra Leone showed that women have significantly poorer access to prosthetic and orthotic services than men. In Malawi, the results suggested a similar trend, but the difference was not statistically significant. In Sierra Leone, patients living in rural areas reported fewer possibilities to access services than those living in urban areas. In both Malawi and Sierra Leone, patients living in rural areas were less able to pay for the costs associated with services. Vulnerable groups are those who are at risk of not being able to access health and rehabilitation services (46). To achieve culturally appropriate and sustainable disability development programmes, the inclusion of persons with disabilities is essential, especially for women, children, older people, and persons living in rural areas, who are often particularly vulnerable (142). Results from the studies included in this thesis indicate that interventions targeting females and patients living in rural areas should be implemented to reduce discrimination against these groups, while providing prosthetic and orthotic services.

Causes of disability and use of assistive devices

In Malawi and in Sierra Leone, the two causes of impairment were trauma and disease, which were roughly equal, although trauma was more common for prosthetic patients. Studies from Vietnam, Cambodia, and El Salvador show that 79% or more of patients had disabilities caused by trauma (90, 91, 97, 99, 100). These studies primarily included below-knee prosthetic users (90, 97, 99). A comparison of the results of these studies and those presented in this thesis needs, however, to be considered with some caution, as the studies in Malawi and Sierra Leone also included above-knee prosthetic and orthotic users. The technology used in producing prostheses was, however, similar. The average age of patients in Malawi and Sierra Leone was 34-36 years, and was quite similar to the studies conducted in Vietnam, Cambodia and El Salvador, where age varied between 35 and 51 years (97).

When investigating the usage of prosthetic and orthotic devices, our studies showed similar results to preceding studies, and confirmed that the majority of the prosthetic and orthotic devices delivered were in use. In Malawi and Sierra Leone, about 90% of the prosthetic and orthotic devices were in use by patients. In Vietnam, Cambodia and El Salvador, 93-100% of below-knee prostheses were in use (97, 99). The average daily use of prostheses and orthoses was 9 hours in both Malawi and Sierra Leone, and consistent with previous studies from Vietnam, Cambodia, and El Salvador, where 8-15 hours of wear time per day was reported (90, 91, 97, 99). Results indicate that the low-cost technology prostheses and orthoses delivered to patients were, used. However, 10% of patients in Malawi and 41% in Sierra Leone preferred to use crutches rather than a prosthetic or orthotic device, at least at certain times. This indicated that the devices were not designed for high activity levels; in Sierra Leone, for example, it was common that amputees played football and they used only crutches. In Malawi and Sierra Leone, about 10 % of patients had a spare device. As patients in Malawi and Sierra Leone had difficulties in accessing follow-up services and repairs, an extra assistive device would leave patients in less vulnerable situations if their regular assistive device breaks. If resources are limited, the first priority should, however, be to provide prostheses and orthoses to those that have not yet received the service, rather than to provide patients with spare devices.

Pain

One third of patients in Malawi and Sierra Leone always or often experienced pain related to usage of their prosthesis or orthosis. In Vietnam, studies reported that between 2 and 10% of amputees experienced pain when using their ICRC polypropylene prosthesis (91, 99). A third study from Vietnam also indicated a similarly low incidence of pain for amputees (90). Three percent of patients in a Cambodian study, and 28% in El Salvador, reported pain while using their prosthesis (97). A larger percentage of prosthetic and orthotic users in Malawi and Sierra Leone reported having pain while using their device compared to the prosthetic users in Vietnam, even though the same ICRC technology was used. The reasons for this may be that, in Malawi and Sierra Leone, about half of the assistive devices needed repairs or replacing entirely, in the Vietnamese study, however, one

quarter of the patients' devices required repair work, and 7% needed a new device (91). A contributing factor to differences in the results might also be that the Vietnamese patients participated in the study roughly two months after receiving their prostheses (91), while in Malawi and Sierra Leone the time since receiving service was longer. The item with the lowest satisfaction scores for assistive devices was comfort, which confirms that pain related to the assistive devices was a major problem. The item with the second lowest satisfaction scores was dimension, indicating that poor dimensioning of the device was also a part of the problem. Another reason could be that the level of education of staff was lower, especially in Sierra Leone. Pain and/or wounds were associated with lower satisfaction of the assistive device in the combined data set, including both Malawi and Sierra Leone.

Mobility

The majority of patients in Malawi and Sierra Leone could walk around their home and on level surfaces, but orthotic patients reported more difficulties than prosthetic patients. The majority could also walk more than a kilometre; 59% in Malawi and 73% in Sierra Leone. In a Vietnamese study, in which two thirds of the participants were above 50 years of age, 79% reported being active or having a high ambulation capacity (100). Other studies reported that 100% of patients in Vietnam, 92% of patients in Cambodia, and 66% in El Salvador could walk more than a kilometre (97). This difference in results could partly be due to the fact that, in Malawi and Sierra Leone, a higher number of patients using above-knee devices and orthotics devices were included. It may also indicate that the prosthetic and orthotic devices and related services delivered in Malawi, Sierra Leone, and El Salvador were of lower quality than those in Vietnam and Cambodia.

About half of the patients had difficulty or could not manage at all when walking on uneven ground, stairs, and slopes. Patients using above-knee devices experienced more difficulties than those using below-knee assistive devices. Most previous studies have not investigated ambulation on challenging surfaces, but one study from Vietnam reported that 93% of prosthetic users could walk up and down steps (90). The ability to walk on

uneven ground and slopes was essential in both rural and urban areas in Malawi and Sierra Leone, as the walking surfaces were unpaved and the rainy season creates rough surfaces. Pain was considered to be an issue when walking longer distances. Polypropylene technology developed by the ICRC was used to produce assistive devices in both countries. Service providers should consider the design of the device so as to facilitate mobility for patients on challenging surfaces, walking on uneven and sloped surfaces (143-145). They should also consider performing a dynamic alignment on challenging surfaces (146) and focusing on training of mobility skills with the prosthesis or orthosis (Article 20c, Table 2) (5). ICRC polypropylene technology often results in prosthetic and orthotic devices with rigid ankles, which may explain some of the difficulties observed in this study regarding walking on slopes and stairs. Gait training is often conducted by the prosthetist/orthotist if no physiotherapist is available. Increased gait training on challenging surfaces and in natural environments, along with providing patients with coping strategies, has been shown to improve gait in amputees using advanced technology prostheses (147), and potentially have the capacity to increase mobility for patients using low-cost technology prostheses and orthoses as well.

Satisfaction of assistive device and service

Patients in Malawi and Sierra Leone reported being quite or very satisfied with their assistive device and with the services received. Patients in Malawi were significantly more satisfied with service delivery than those in Sierra Leone. However, in open comments patients in both countries reported numerous problems with their device. A study of Haitian amputees reported similar results for prosthetic and orthotic services. However, patients in Haiti were more dissatisfied with the cosmesis of their prosthesis (94). Studies conducted in Iran (103), the Netherlands (148, 149), and the United States (150-152) indicate equal or less satisfaction when compared to patients in Malawi and Sierra Leone. These studies did not, however, use the same instrument to measure satisfaction as in this thesis.

It is important to recognise that quality indicators for service provision should include more than simply patient satisfaction (45). Quality of services

can, for example, be measured in terms of the comfort, durability, and performance with an assistive device (45). In a review of patient satisfaction and rehabilitation, it was concluded that the measure of patients' satisfaction within rehabilitation should include items regarding progress towards independent living (153) which is not included in QUEST 2.0. Patient satisfaction with assistive devices can be affected by expectations, previous experiences, life conditions, and healthcare values (154, 155). The fact that many of the patients had never received any prosthetic and orthotic services before the centre in Malawi, Lilongwe opened may have contributed to the high level of satisfaction reported. It is likely that patients in Malawi and Sierra Leone had relatively low expectations, and subsequently it is important that reported satisfaction is not used as the sole indicator of quality. The results from Malawi and Sierra Leone suggested that patients highly value the prosthetic and orthotic device and services they received. However, these results were based on self-reported data, and one cannot rule out the possibility that patients felt that they needed to be thankful for the services they received and that this may have influenced the results.

Regression analyses using combined data from Studies I and II demonstrated that the ability to walk on uneven ground was influencing the level of satisfaction with assistive devices and services. This corresponds well with the results of the content analysis of the qualitative comments, in which limitations to the effectiveness of the assistive device, was the second largest category in Malawi and the third largest in Sierra Leone. Regression analysis also indicated that satisfaction of assistive devices was influenced by pain when using the assistive device which also corresponds well with qualitative comments where lack of comfort and pain was the largest category. Phantom pain and level of amputation have previously been associated with prosthetic use in elderly patients (156). Regression analyses indicated that the condition of the device was a variable associated with satisfaction with both the device and service. This indicated that follow-up services and access to repairs were considered as most important. It is likely that a lack of finances has a major effect on access to follow-up services and repairs.

Results discussion; Studies III and IV

Culture and negative attitudes affect prosthetic and orthotic service delivery

Local professionals in Sierra Leone reported that persons with disabilities had low social status within society. This was confirmed in the United Nations report on the rights of persons with disabilities in Sierra Leone (38), which aimed to analyse factors that contributed to realising the rights of people with disabilities. In this report, societally and culturally negative attitudes were perceived as the biggest obstacle in achieving inclusion for persons with disabilities (72). Negative attitudes and traditional beliefs were strong in Sierra Leone, especially in rural areas. The previous findings from focus group discussions indicated that people with disabilities were seen as products of witchcraft, and sometimes not seen as fully human (38). Stigma and attitudes towards persons with disability were rooted in the languages used in Sierra Leone, and persons with physical disabilities were often called crippled or 'die fut ahn'; 'dead feet' or 'dead hands' in Krio. Children with severe disabilities were referred to as 'debul pikin'; which means 'devil' or 'demon child'. Amputees were often called 'one leg' (38). It is also known that persons with disabilities in Sierra Leone had difficulty accessing education, employment, and healthcare (39). The findings in this thesis suggested that such difficulties also exist in terms of accessing rehabilitation services. Sierra Leone has paid limited attention to disability issues due to the fact that many other areas needed urgent attention after the long civil war. However, the government of Sierra Leone has recently shown an increased commitment to disability issues by ratifying the CRPD in March 2011 (13), and passing the enactment of the Person with Disability Act (82). Despite this, those with disabilities in Sierra Leone continue to face discrimination, even though the CRPD and the disability act are important recent changes at a policy level. These changes will lead to improvements for persons with disabilities in Sierra Leone, provided the policies are put into practice at multiple levels within the society.

Poverty affects access to prosthetic and orthotic service delivery

Small registration costs and hidden fees, paid to staff in order to access prosthetic and orthotic services, were identified as a hindrance for persons with disabilities in Sierra Leone. The country is moving towards a development stage, and the Sierra Leonean government has taken over many of the relief services initiated by international organisations during the emergency phase which preceded the war (157), including some of the rehabilitation centres providing prosthetic and orthotic services. The government introduced user fees for services that were provided after the war for free by non-governmental organisations, which has affected persons with disability. The open comments made by patients in Study II called for more transparency with regard to fees for prosthetic and orthotic services in Sierra Leone.

Difficulties in managing specific conditions, including diabetes

In Pakistan, road traffic accidents were reported as the most common cause of amputation, followed by diabetes (158). Results from Pakistan suggest diabetes as an area requiring specific attention. The disease was identified as one of the most common causes of amputation, and staff mentioned that they had very limited knowledge of the area. Results supported the findings of Soomro and Jalal (158), who call for an agenda for diabetes prevention and care in Pakistan. Knowledge about management of diabetic patients requiring prosthetic and orthotic devices needed to be implemented in the PIPOS educational curricula and as a course available to staff providing services for these patients in Pakistan. This is of particular importance as low-cost technologies are commonly used, and care is required on the part of the prosthetist/orthotist so as to avoid wounds which in turn create further complications and reduce mobility.

The desire for improvements in prosthetic and orthotic education, and opportunities for further professional development

Staff in Pakistan revealed that there was a desire for improvements in the educational programme at PIPOS. The ISPO report of 2010 indicated a high student failure rate and a number of issues related to curricula and teaching methodology which required attention. A questionnaire was carried out in 2010 at PIPOS, answered by the students. Few graded their education and their teachers' behaviour as good. About half of the students considered the teaching methodology reasonable, while 27% felt that it was poor or very poor (159). An ISPO follow-up visit in 2011 reported that PIPOS had made some changes to better prepare students for clinical placements, and had started to revise the manuals used in teaching (160). The findings in this thesis show that the Pakistani prosthetists/orthotists wanted further professional development and the opportunity to pursue higher degrees in prosthetics and orthotics. The 2012 ICRC annual report indicated that a number of Pakistani prosthetists/orthotists were enrolled in further education at TATCOT and at the National Centre for Prosthetics and Orthotics at Strathclyde University (83). This indicated that some prosthetists/orthotists have managed to access further professional development as desired.

The training and employment of female clinicians is considered important for the provision of prosthetic and orthotic services for women (84). A survey of all amputees visiting a rehabilitation centre in Karachi between 2007 and 2009 showed that 85% of patients were male and only 15% were female. The authors further discussed that men are the financial providers, and are subsequently more exposed to the hazards of traffic accidents and work-related injuries (158). This could, however, also be partly due to the fact that female patients do not have equal access to rehabilitation services in Pakistan. Female prosthetists/orthotists are needed in the country, and they deserve to be treated equally by teachers and others in the profession. PIPOS educates females, and about 35% of the graduates are women. However, findings from interviews revealed that there is a risk that female prosthetists/orthotists in Pakistan stop working after a period of time in order to stay at home. This reduces the already limited educated workforce that

provides prosthetic and orthotic services. General employment statistics confirmed this risk, reporting that only about 30% of the women with degree-level education in Pakistan were part of the workforce (161).

An additional study, of how Tanzanian and Malawian graduates of the Diploma course in Orthopaedic Technology at TATCOT perceived their education in relation to their profession (162), was conducted by LM. The interview guide was similar to that employed for Study IV, and a phenomenographic analysis was applied to the data. The common findings in Sierra Leone (Study III), Pakistan (Study IV), Malawi, and Tanzania [unpublished study (162)] demonstrated that managing specific pathological conditions and problems with materials were common difficulties perceived by graduates from both schools. A need for further education and a desire for professional post-graduation development were also common themes. PIPOS (Study IV) and TATCOT (Unpublished Study) graduates desired and perceived a need for improvements in the education programmes. They perceived that more time needed to be dedicated to applied biomechanics and the clinical management of various specific orthotic and prosthetic patient groups, such as cerebral palsy, upper-limb prosthetics, and spinal orthotics. They also perceived a need to include education related to advanced prosthetic and orthotic technology. Both PIPOS and TATCOT participants perceived that technical drawing could be dropped, and metal- and woodwork reduced in the curriculum. Participants from both schools expressed a desire for teachers with higher degrees. It was expressed that inequality in the treatment of students needed to be addressed within both education programmes. In Pakistan, female students were not given the same opportunities as male students and, at TATCOT, Tanzanian students were perceived as receiving better treatment than international students.

Prosthetic and orthotic services in relation to poverty and the CRPD

The provision of prosthetic and orthotic services is subsequently a vital step towards implementing the CRPD. The results from Malawi and Sierra Leone (Studies I and II) showed that prosthetic and orthotic devices clearly increase

the mobility of persons with lower-limb amputations and lower-limb impairments. The negative circle of disability and poverty (31) can be reduced by offering persons with physical disabilities increased mobility through provision of prosthetic and orthotic devices. This can facilitate increased inclusion in mainstream services such as education, employment, and healthcare services, as well as participation in political and public life. Increased inclusion can lead to reduced poverty for persons with disabilities. Several studies have investigated the association between disability and poverty, and proposed that the two are linked (30, 33, 35). There are, however, contradictory findings amongst several studies (6), and one literature review concluded that the evidence base for the links between poverty, disability, and health are weak (163). In a household survey of 14 developing countries, the association between poverty and disability was reduced in most countries after controlling for education (36). The relationship between poverty and disability still requires a more nuanced analysis in order to determine which factors are most important to target (164), and in order to provide recommendations for global policy and development programmes (163).

The World report on disability (6), the Washington Group on Disability Statistics (165), and work published by Bickenbach (25) suggest that the CRPD and ICF biopsychosocial concept of disability are aligned. The CRPD requires states that have ratified the convention to also implement monitoring mechanisms for the CRPD. However, creating indicators to monitor the CRPD is a challenge. An attempt to develop indicators for monitoring Article 26 of the CRPD, covering rehabilitation, suggested that the ICF framework could serve as a bridge for various terms used in available data resources in different states as indicators to monitor the CRPD. In addition, gaps in the implementation of rehabilitation (Article 26, CRPD) could also be categorised according to the ICF (25). The Washington Group on Disability Statistics has developed, a set of disability-related questions that cover six functional domains: seeing, hearing, walking, cognition, self-care, and communication suitable for use in national censuses, that can be used to monitor the CRPD (165).

Prosthetic and orthotic services in relation to the ICF

The ICF model which describes both problems in functioning, in body, activity performance and participation as well as environmental factors that influence function (26). The ICF model is therefore suitable for application in the process of provision of assistive devices (166, 167). The ICF provides a common language (168), and can be of assistance when relating medical aspects of a patient's condition and treatment such as (polio; orthotic), to function (walking, activities of daily living) and participation (education, work, hobbies) (166). The ICF can be used in policy documents and for describing groups of patients requiring prosthetic and orthotic devices (166). The ICF may also be of use in the education of prosthetics and orthotics staff (168), as the ICF describes different components of health (26) and includes both a medical and social perspective of disability. However the literature also points to a number of reasons why the ICF alone is not sufficient as a tool for use in relation to prosthetics and orthotics research or as a clinical tool. Further development of the ICF for groups of users of orthoses and prostheses and/or more detailed outcome measures are required if the ICF is to be used to investigate the functioning of prosthetic and orthotic devices for these purposes (166, 167, 169). As core sets not yet developed its not yet suitable as a clinical tool. It enables coding of environmental factors, which includes assistive products and technology for personal use in daily living, but the categories for environmental factors are too general and prosthetic and orthotic devices belong to a category which includes a wide range of different assistive devices and products (167). Many ICF activity and participation codes are not specific enough to describe the function of prosthetic and orthotic devices (167), for example, the ability to walk on challenging surfaces would not identify which biomechanical aspects need to be prioritised and addressed. In order to receive necessary information about patient problem additional sub-categories need to be added or additional outcome measures. Using the ICF for research before adjusting and developing sub-categories to suit investigations of functioning with prosthetic and orthotic devices might lead to the collection of data which is too general in scope (169). Work is currently ongoing to produce an ICF core set for persons following an amputation (170) and one initial paper was found defining the need for lower-limb orthoses core set (171).

In an American study which investigated the environmental factors for persons who had suffered with strokes, traumatic brain injuries and spinal cord injuries (172), was indicated that the ICF categories related to environmental factors are relevant but lack a domain concerning economic quality of life. This corresponds to the results of Studies I and II in this thesis, where income and ability to pay for services and related costs clearly affect participants' functioning, as many of the orthoses and prostheses were broken but still in use. An Irish study addressing environmental barriers for lower-limb amputees indicated that climate, physical environment and income were the top three environmental barriers to functioning (173). Income and physical environment appeared as barriers in Studies I and II, although very few of the problems described were related to climate. It is possible that poverty affects functioning in a more critical way in low income countries than in high income countries. However no studies were found by the author investigating environmental factors according to the ICF for persons with disabilities in low income countries has been identified. ICF has the ambition to be international classification therefore economic aspects need to be included as environmental factors and/or personal factors.

Relating the studies in this thesis to the International Classification of Functioning, Disability and Health

Figure 6, illustrates patients, lower-limb amputation and lower-limb physical impairment and examples of variables examined in Studies I and II, and examples of the results in Studies I-IV that can be related to the ICF. Mobility for prosthetic and orthotic users was investigated, and variables were chosen based on clinical aspects relevant to prosthetic and orthotic service delivery. A number of the variables investigated regarding mobility (Studies I and II) correspond to the ICF categories for activities and participation see Figure 6. The barriers and facilitators identified while providing prosthetic and orthotic services in developing countries can be related to the ICF's environmental factors; products and technology, natural environment, support and relationships, attitudes, and service systems and policies. Examples of results from Studies I-IV that were related to the ICF's environmental factors are presented in Figure 6. Personal factors are, according to the ICF, those not related to health condition and health states.

In this thesis, sex and nationality are examples of personal factors which are used as variables to describe the sample and compare sub-groups (26).

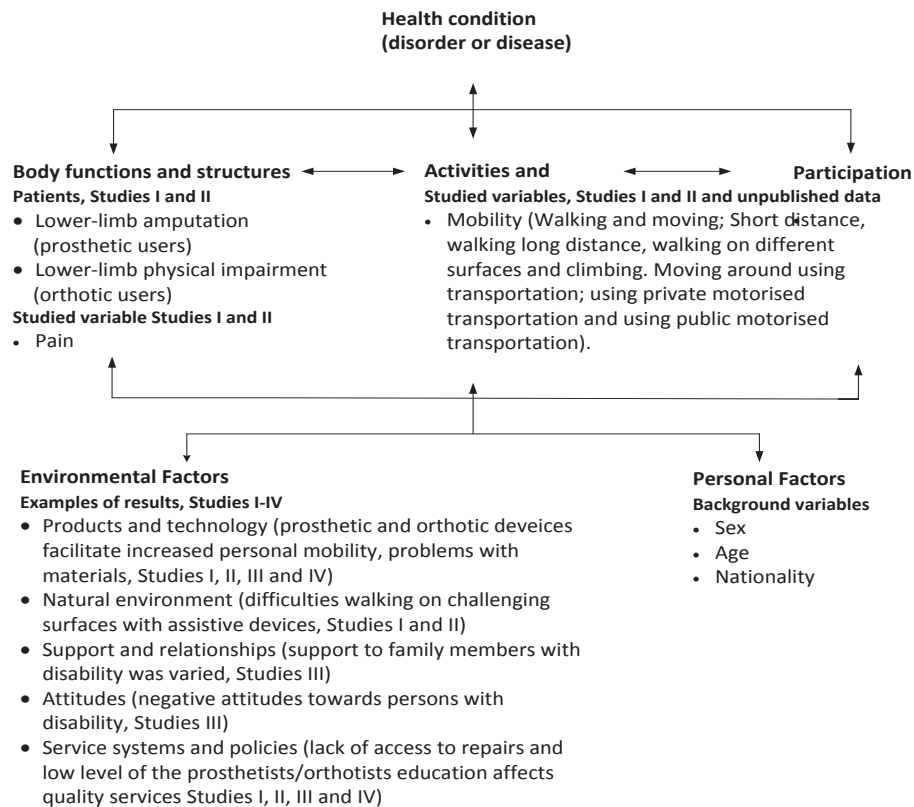


Figure 6: Variables studied and examples of results of studies in this thesis relates to the Classification of Functioning, Disability and Health

Pain is, according to the ICF classification a, bodily function, while assistive devices are an environmental factor (26). In Studies I and II, patients were asked if their assistive device caused pain. This is an example of an item, “pain” which occurs in the interaction between body structures (amputee or person with physical impairment) and environmental factors (prosthesis or orthosis). Existing ICF qualifiers can be used to demonstrate the impact of a prosthetic or orthotic devices on a person’s functioning (169). An example

of performance (26) in this thesis is patients' reported ability and difficulties when walking using their assistive device, while capacity is the patient's ability to walk without using an assistive device. Measures such as level of satisfaction of assistive device and services are not included in the ICF and nor qualifiers such as activity completion time or safety. This is seen as limitation (167), and thus, other outcome measures are needed as complements to the ICF.

Methodological discussion; Studies I and II

Sample

Studies I and II were designed to include patients who had received prosthetic and orthotic devices and services. The patients who were in the prosthetic and orthotic rehabilitation centres' registers were contacted and included. However, the studies in this thesis provided no information about those who had not received any services. For the period between April 2009 and December 2010, there were 196 patients in the registers at the centre in Lilongwe, Malawi, and 553 patients in all of the centres in Sierra Leone who had received lower-limb prosthetics or orthotic devices and were above 15 years of age. Patients in Malawi (Study I) were recruited from one of the two centres in the country. The centre in Blantyre, which was not included in the study, had approximately 500 patients who fulfilled the inclusion criteria over the same time period. The centres in Lilongwe and Blantyre provided similar services, and the education level of the staff at the two centres was very similar. Patients who were below 15 years of age and those who had received upper-limb and trunk prostheses and orthoses were not included. There were also a number of patients who had received services, but outside of the timeframe of the research, these were not included in the study. In Malawi, some patients received assistance in covering costs for prosthetic or orthotic devices every three years (Personal communication, Tone Oygard, November 2010). Malawi's population is 17 million, while Sierra Leone's is 6 million. Household surveys conducted in Malawi in 2004 indicate that only 11% of persons with disabilities who would benefit from assistive devices had received services (37). In Sierra Leone, reports estimated that

approximately 10,000 people (174) were in need of prosthetic and orthotic devices. Injuries caused by the civil war, accounted for approximately 5000 new upper-limb amputees (175) and 1000 new lower-limb amputees (174). When comparing these figures to the number of patients in the rehabilitation registers, one may conclude that either the statistics are not accurate regarding how many people need assistive devices, that those people have not survived, or that there are a high number of people not receiving services. Additional questions regarding whether the patients were aware of prosthetic and orthotic patients not receiving services, or if they know of prosthetic and orthotic users who had died, could have provided some of this missing information. It is, therefore, important to remember that Studies I and II of this thesis only included a sample of those who had received services. It is likely that the remaining persons in need of prostheses and orthoses who still had not received any services were not as satisfied as those who had received services from one of the rehabilitation centres. It is also an indication that services need to be scaled up so as to reach persons with disabilities who have not yet had the possibility to receive a prosthesis or orthosis.

This thesis includes patients with a weakness or deformity that requires an orthotic device, and amputees who require a prosthetic device. Both groups have a physical impairment and experience difficulty ambulating. Mobility and satisfaction with assistive device and service are relevant outcome measures for both groups, and are considered to be of importance to this thesis. Previous studies from developing countries have most commonly included only amputees (110). Furthermore, a study from Afghanistan demonstrated that orthotic patients have less access to services than prosthetic patients (176). In addition to comparing prosthetic versus orthotic patients, a comparison of groups based upon level of impairment was also considered to be of interest. Persons who have an amputation or weakness/deformity below the knee require a less advanced biomechanical prosthetic/orthotic design than those with above-knee, impairments as only one major joint is affected/missing. Due to the differences in aetiology, the results of these comparisons need to be considered with some caution.

Patients in Sierra Leone (Study II) were largely recruited via key contact persons and home visits, since the patient registers had very few telephone numbers. Key contact persons, living or working in communities where many persons with disabilities resided, assisted in contacting the patients who were found in the registers. Through these people, patients in the registers were identified and contacted in amputee camps, boarding schools for children and young people with physical disabilities, and through polio support groups. In addition, several organisations assisted in contacting and inviting patients; these organisations included the Polio victim association for women and girls, a vocational training centre for boys, and football teams for amputees. Through the assistance of these key contacts, it was possible to include both female and males and persons of varied socioeconomic status, even though the majority were very poor. It is therefore unlikely that the method of recruitment has resulted in an overrepresentation of males, or people with telephones who could potentially be socioeconomically 'better off'. Drop-out analysis confirmed that there was no overrepresentation of males.

Translations of the questionnaire

In order to translate the questionnaire, the following steps were taken: forward translation, expert panel, back-translation, pre-testing, and cognitive interviewing (124). No specific validation study of the Chichewa (Study I) and Krio (Study II) versions of the questionnaire were conducted. Translations were discussed amongst the translators in order to reach a consensus regarding the most appropriate words in Chichewa and Krio. Inadequate expressions in the translations and discrepancies between the forward translations were identified and resolved. In Sierra Leone (Study II), the translations were discussed by an additional panel of bilingual experts, which included two of the original translators, the researcher, and two of Handicap International's local staff members, who worked with disability issues and the provision of prosthetic and orthotic services. The local staff from Handicap International was familiar with the words commonly used within the field of disability and rehabilitation. One of them was a person with a disability and a user of an assistive device. Panel discussions were necessary as Krio is primarily a spoken language, so it proved to be a

challenge to translate several words in the questionnaire. Phrases were used when no specific words existed; for example, 'durability' was translated to 'how long did they last', and the Krio translation of 'device' was 'thing that helps you walk'. The English word 'wheelchair' was used, as the alternative in Krio, 'push push', refers only to those types of wheelchairs that a person cannot operate themselves. It was difficult to find an appropriate translation for 'amputation' in Krio, as the local phrase in Krio means someone whose leg has been cut, which has negative connotations and refers to amputations which occurred during the war, rather than to those which may have had other causes. No better translation was found, in spite of the fact that the person with a disability in the meeting felt that the phrase was offensive. The best solution that the panel could find was to say the word in a positive manner, with a kind voice. The questionnaires were back-translated to English from Chichewa by a rehabilitation professional (Study I) and to Krio by a social worker (Study II). The back translations were compared with the original English version by the researcher, and were found to be almost identical. A few minor differences were identified and discussed with the staff at the prosthetic and orthotic centre in Lilongwe, Malawi (Study I), and with the Handicap International staff in Sierra Leone (Study II). Minor changes were made, and the questionnaires were edited for spelling errors. The questionnaires were pilot tested on three patients. In Malawi, the word 'comfort' proved to be a problem as it referred to the comfort in both a physical sense and a social setting. In Sierra Leone, the Krio-speaking research assistants highlighted some words that were incorrectly translated, and these minor issues were discussed and corrected in both Malawi and Sierra Leone. The final versions of the questionnaires in Chichewa and Krio were fully comprehended and understood by the patients included in the studies.

Research assistants and interpreters

The translated questionnaires were read to patients by local research assistants/interpreters due to low literacy levels. Before data collection began, the assistants were recruited, and their ability to read Krio and Chichewa was assessed. It was considered necessary that the research assistants were not involved in delivering the prosthetic and orthotic services

to the patients included in the study (177). A meeting with the interpreters prior to data collection was recommended (128, 177). Local research assistants were initially given information about the study and were provided with training which included information related to research ethics, attitudes towards patients, and preferred ways of interpretation, such as avoiding summarising, expressing their own opinion, or talking about a patient or researcher in the third person. Use of the same interpreter was also recommended (128), however, in Study II this was not preferable, as patients spoke Krio as well as a number of additional tribal languages from the different regions of Sierra Leone, and therefore different interpreters were used. The presence of a local research assistant changes the dynamic of the interview (178), and in Studies I and II the local research assistants read all of the questions in Krio or Chichewa. The presence of an interpreter could potentially have influenced the way the patients answered.

Validity and reliability

Previous studies have been conducted to measure content validity for the English version of QUEST 2.0. Experts from the Netherlands, Canada, and the United States rated the relevance of items included in the questionnaire in relation to the scope of satisfaction of assistive devices and service. They concluded that the items were relevant, but that the wording could be changed (117, 179). Construct validity for QUEST was tested with factor analysis, and the results demonstrated that items clustered together to form two dimensions of satisfaction of assistive technology, satisfaction of assistive device, and satisfaction of services (117).

Measuring satisfaction is dependent upon clear definitions, and this can have an effect on reliability (180). Test-retest reliability and internal consistency for the English version of QUEST has been studied, and the resulting reliability coefficient of 0.8 was considered to be good (119). Another aspect of reliability in this thesis is the internal consistency/homogeneity of the Malawi and Sierra Leone translations of QUEST sub-scales. Cronbach's alpha for the QUEST sub-scales for satisfaction of assistive device and service for English, Chichewa, and Krio translations demonstrated good internal consistency, with the exception that the Chichewa translation for

'service' showed a low Cronbach alpha of 0.4, probably due to the ceiling effect resulting in a low scattering of data. Previous studies of the English (119), Dutch (118) and Taiwanese versions (126) of QUEST reported high reliability. In summary, the English version of QUEST has been demonstrated to have good validity and reliability (118, 119).

In the studies in Malawi and Sierra Leone using QUEST 2.0, 67 qualitative comments, (5 % of the total comments), related to lack of money. In validity and reliability tests of 16 additional culturally-specific items added to the Taiwanese version of QUEST, the only additional item included was 'costs', which was added to the service delivery domain (126). Cost or lack of money was also shown to have an association with the service delivery of assistive devices in Sierra Leone and in the combined data set. The item related to cost might subsequently be relevant to include in QUEST if conducting a validation process of the instrument in low-resource settings. Additional questions constructed for Studies I and II regarding background, mobility, and service delivery were not standardised or tested for validity or reliability, which is a limitation.

In the questionnaire (Study I and II), the statement about pain was phrased “My assistive device causes me pain while using it.” Previous studies have shown that amputees experience pain in different forms; residual limb pain, phantom limb pain (181, 182), back pain (183-185), and pain as a result of using assistive devices. Different types of pain often overlap and can be experienced at the same time. As a result, reported pain might not necessarily be related entirely to usage of an assistive device. A previous study has also indicated that amputees who experience phantom pain and residual limb pain prior to provision of an assistive device reported lower levels of satisfaction with their prosthesis than amputees who did not (186). A limitation of this thesis, then, is that different types of pain were not measured.

Number of patients in the groups studied

Power calculations for QUEST 2.0, which were conducted in the planning phase, indicated that approximately 160 patients should be included in order

to detect a difference between two groups with a power of 80% if the true difference between groups was 0.3. It was not possible to include 160 patients from each country due to the fact that the centre in Blantyre did not have contact details for most of the patients in their registers. It should be noted that patient details in registers at the time of planning the study were maintained in handwritten form at each site. It was therefore difficult to obtain more detailed information on potential numbers in different sub-groups when planning the study. Few significant differences between groups were detected in Malawi (Study I), indicating that there was not sufficient power to detect differences, or there were few differences between sub-groups. In Sierra Leone (Study II), there were several statistically significant differences between groups, indicating that there was enough power to detect clinically relevant group differences.

Data analysis

A ceiling-effect and skewed distributions were observed in the Malawi data for satisfaction of service, which can be considered as a limitation. The data for satisfaction of assistive device (Studies I and II) and service in Sierra Leone (Study II) were more symmetrically distributed.

In Sierra Leone (Study II), the results indicated that persons living in rural areas experienced less difficulties when walking on stairs than those from urban areas. It could be that stairs are rare in rural areas and, because of this, these patients less frequently report an inability to walk on stairs than those from urban areas, therefore, this result should be considered with caution.

Multiple statistical tests were carried out when comparing groups, increasing the likelihood of type 1 errors. There is a possibility that some of the observed statistically significant differences between groups were due to chance. For this reason, weak significances should be considered with caution, and the conclusions are subsequently based on the overall patterns of significant differences (Studies I and II). Linear regression analysis was used on total subscale scores for satisfaction of assistive device and service on the combined data set of Studies I and II. Residual analysis was

conducted on final regression models, indicating that linear regression was not inappropriate to use.

Methodological discussion; Studies III and IV

Trustworthiness

Sampling strategies can affect credibility. Strategic sampling was conducted (187) for staff delivering the prosthetic and orthotic services in Sierra Leone and Pakistan (Studies III and IV). Participants with varying experience and backgrounds were included to obtain variation and increase the credibility. In Studies III and IV, credibility was strengthened by the inclusion of participants working in different employment situations. In Sierra Leone, the prosthetic and orthotic technicians were all males, but in Pakistan both females and males were included.

To increase dependability, interview guides were used in Studies III and IV. The same basic lines of questioning were used, in addition to probing questions so as to obtain more information. Examples and clarifications were also used (187). In Study III, the interview guide consisted of only a few broad questions during the first interview, and more in-depth questions during the second. In-depth questions were developed after the preliminary analysis of data from the first interview. Three pilot interviews were performed in Study IV, and one question was added concerning gender equality after the pilot interviews.

The interviewer and participants represented different nationalities and cultures and the interviews were conducted in English, which was the second language for both parties (Study III and IV). This may have affected the communication and credibility of the studies, even though all participants spoke English fluently. It is likely that the females in Pakistan were more comfortable sharing their experience, as they were interviewed by a woman rather than a man. To increase the credibility of Study III, data collection in Sierra Leone was extended over two interviews, providing the opportunity for prolonged engagement (188) to further explore and acquire a greater

understanding of a culture that is not the author's own. Although use was made of an interview guide based on the sub-themes emerging from the analysis of the first interview, the interviewer kept an open mind with regard to possible new findings on the second occasion. Credibility was strengthened in that the author had previously worked with healthcare and rehabilitation within several low income contexts, and the second author of Study III, GA is experienced in qualitative research and working with data from different cultures. Together, every meaning unit and code was examined, and the two authors were both involved in creating the final sub-themes. A limitation of the study was that no local person was involved in data analysis and the writing of the manuscript. All of the sub-themes that were generated as a result of the data collection on the first occasion were enriched with more data from the second. Two new sub-themes (Paper III, Table I) did emerge at this point; problems with materials and machines, and appraisals of work satisfaction and norms. These two sub-themes were extracted from the three centres that had been handed over to the government between 2006 and 2011. The former non-governmental organisations responsible for the service had handed over the responsibility of importing materials for the production of prosthetic and orthotic devices, and so the staff had become employees of the government. The content analysis for Study IV, the transcriptions, meaning unit condensations, codes, and preliminary categories were processed by LM. To strengthen credibility, the second author NR was involved in the process of creating categories and themes. NR had experience of prosthetic and orthotic education in a number of high income countries.

Transferability of findings; Studies I-IV

The external validity/transferability of the results of the studies depends on the similarity of the context and the staff and patients participating, and the design of the studies. The studies provide contextual knowledge related to the countries of origin, and generate knowledge in a field that has been relying on expert opinion and in which very little research has previously been conducted (8, 108, 110). Therefore, the knowledge produced adds to the available research, and could contribute to guidelines for prosthetic and

orthotic services and education in low resource settings, even though further research is recommended.

Conclusions

The majority of lower-limb prosthetic and orthotic patients reported being mobile while using their device, although a third often experienced pain and more than half had difficulties walking on uneven ground, walking up and down hills, and on stairs while using their assistive device.

Lower-limb prosthetic and orthotic patients were quite satisfied with their assistive devices. The patients in Malawi were very satisfied with the service received, while patients in Sierra Leone were quite satisfied in spite of the fact that more than half of the assistive devices were in need of repair. Access to repairs and follow-up services were important to patients, and should be addressed by both professionals operating within the rehabilitation field and policymakers.

Patients using above-knee devices were less satisfied with the services received than patients with below-knee devices. Women in Sierra Leone had poorer results when compared to men in terms of both mobility and satisfaction of assistive device and service.

The variables associated with higher satisfaction with assistive devices were absence of pain, condition of the device, and the ability to walk on uneven ground, on stairs, and to get in and out of a car. Higher satisfaction with services was associated with country, condition of the device, ability to walk on uneven ground and on stairs, and the capacity to pay for costs associated with receiving services.

The perspective of local professionals was that they had a sense of inability to deliver high-quality prosthetic and orthotic services. Educating prosthetic and orthotic professionals to a higher level and providing opportunities for professional development was desired. Low awareness and low priority on behalf of the government when it comes to prosthetic and orthotic services was identified as a barrier to providing effective rehabilitation.

In Sierra Leone, people with a disability needed to be included to a greater extent and supported at different levels within families, communities, government, international organisations, and society in general. Traditional beliefs about the causes of impairment and difficulties in accessing services were identified as barriers to providing effective rehabilitation services.

In Pakistan, prosthetic and orthotic education could be improved by modifying programme content, upgrading teachers' knowledge, improving access to information, and addressing issues of gender equality.

The CRPD promotes the rights to access, to personal mobility, and to rehabilitation services, including prosthetic and orthotic services for persons with disabilities. In summary, this thesis demonstrated that there was still a need for significant progress in the promotion of equal rights and the implementation of rehabilitation services to persons with disabilities according to the CRPD, in order for persons with disabilities people to have increased opportunities to take part in society.

Implications

The findings of the studies included in this thesis provide numerous implications for the continued provision of prosthetic and orthotic services in Malawi, Sierra Leone, and Pakistan.

In both Malawi and Sierra Leone, patients' self-reported mobility and satisfaction of assistive device revealed that the design and manufacture of prostheses and orthoses using low-cost technology needs be improved. A focus on improvements in service delivery needs to be directed specifically towards increasing the ability of patients to ambulate on uneven surfaces, hills, and stairs, as well as increasing patients' ability to walk long distances with reduced pain and without causing wounds. Increased or simulated ankle joint range of motion, careful dynamic alignment, more optimal dimensioning of assistive devices, and improved training could facilitate the desired improvements.

To increase patients' satisfaction, attention needs to be directed towards accessing follow-up services and repairs, and addressing the general condition of assistive devices. Financial support for transport is also needed so that patients can manage to reach the rehabilitation centre by public transport.

Interventions targeting females and orthotic patients should be implemented to reduce discrimination against these groups.

In Sierra Leone, the quality of assistive devices and service delivery could be enhanced by addressing the education level of staff, where an increased number of staff and a higher proportion of service-providing staff should have a minimum of three years of internationally recognised education.

At the societal level in Sierra Leone, both traditional beliefs about the causes of disability and public attitudes need to be changed in order to include and assign human rights to people with disabilities. Support from international organisations is needed to provide effective rehabilitation services. There is

also a need to make materials available for the fabrication of prosthetic and orthotic devices.

To provide more appropriate and efficient rehabilitation in Pakistan, there was a need for clinicians to improve skills and knowledge. The implementation of changes needed to consist of modifying the content in education programme, upgrading teachers' knowledge, and improving access to information for students. In order to facilitate services for female patients in Pakistan, PIPOS need to continue to educate female prosthetists/orthotists, but also give them equal opportunities during their education. Opportunities for professional development for prosthetists/orthotists in Pakistan need to be created.

To implement the CRPD, prosthetic and orthotic services need to be scaled up in developing countries and provided to all persons with disabilities who could potentially benefit from prosthetic and orthotic devices. This is an urgent issue, when many today have yet not received any services at all.

Future research

In the field of research concerning prosthetic and orthotic services in developing countries, there were very few studies with a high level of methodological quality that generated generalisable knowledge which can be used to establish national and international recommendations (189, 190). The majority of the studies conducted until the time of writing within the field have been quantitative studies that have investigated a specific product. However, the study designs are often rather poor as compared to what is recommended by WHO (189) so as to be used as a basis for international guidelines.

Qualitative research allows us to explore how patients or staff experience different prosthetic and orthotic solutions, as well as understanding more thoroughly what works well, and not so well, within the service provided. Few qualitative studies have been conducted within the field of prosthetics and orthotics (109). Qualitative studies are, therefore, of importance, even if

this type of design does not produce generalisable knowledge. Further research is also needed to increase the focus on orthotic patients, women, and those who have yet not received any services at all.

Cost-effectiveness in providing access to follow-up services needs to be investigated. Low-cost technology, developed by the ICRC, is used to produce both prosthetic and orthotic devices. The ICRC low-cost technology for orthotic devices has been evaluated less frequently than for prosthetic devices (89), even though these services are provided by the same profession. Less than 10% of the research published in relation to prosthetic and orthotic devices and services in developing countries concerns orthotics (109), suggesting that this area requires attention. In addition, there is a need for research and further product development related to the low-cost technology that is most appropriate in developing countries and which can be mass-fabricated and provided at a reduced price.

Summary in Swedish

Svensk sammanfattning

Introduktion

Denna avhandling handlar om ortopedteknisk service i utvecklingsländer, patienters och professionellas syn på ortopedteknisk service i Malawi, Sierra Leone och Pakistan. Ortopedtekniska hjälpmedel och service behövs för att implementera Förenta Nationernas konvention om rättigheter för personer med funktionsnedsättning, vilken föreskriver att människor med funktionsnedsättning har rätt till personlig rörlighet (Artikel 20), och rehabilitering (Artikel 26). För att få bästa möjliga personliga rörlighet har människor med funktionsnedsättning rätt till kännedom om, tillgång till och användning av specialanpassade ortopedtekniska hjälpmedel. Tillgången på ortopedteknisk service är begränsad i många utvecklingsländer och behöver utökas. Ortoser och proteser kan ge möjlighet till ökad rörlighet för personer med funktionsnedsättning vilket kan underlätta tillgång till andra basala rättigheter som mat, bostad, utbildning och inkomst. Ortopedteknisk service och försörjning av ortopedtekniska hjälpmedel påverkas av policy, fattigdom och kulturella aspekter som attityder gentemot personer med funktionsnedsättning. Hindrande och underlättande faktorer för försörjning av ortopedtekniska hjälpmedel behöver identifieras för att kunna förbättra ortopedteknisk service i utvecklingsländer. Det behövs också fortsatt utveckling av lågkostnadsteknologi för ortopedtekniska hjälpmedel. Majoriteten av utvecklingsländer bedriver ingen ortopedteknisk utbildning vilket resulterar i en brist på personal som kan leverera kvalificerad ortopedteknisk service till personer med funktionshinder i många utvecklingsländer.

Det övergripande syftet med denna avhandling var att generera fördjupade kunskaper om ortopedteknisk service i utvecklingsländer. Avhandlingen fokuserar på att undersöka patienters personliga rörlighet och tillfredsställelse med ortopedtekniska hjälpmedel och tillhörande

ortopedteknisk service samt professionellas syn på klinisk praktik och utbildning.

Metoder

Deskriptiva, explorativa och jämförande undersökningsmetoder har använts i de fyra studierna som avhandlingen bygger på. Frågeformuläret QUEST 2.0 användes för att samla in självrapporterade data från 83 patienter i Malawi och 139 patienter i Sierra Leone. Kvantitativ data analyserades med icke-parametriska tester och linjär regression. Dessutom intervjuades 15 ortopedtekniker i Sierra Leone och 15 ortopedingenjörer i Pakistan. Intervjuerna analyserades med latent och manifest innehållsanalys.

Resultat

Majoriteten av de deltagande patienterna använde sina proteser eller ortoser (90 % i Malawi, och 86 % i Sierra Leone), trots att ungefär hälften av hjälpmedlen var trasiga och behövde repareras. Drygt en tredjedel av patienterna rapporterade smärta vid användning av sina hjälpmedel (40 % i Malawi och 34 % i Sierra Leone). Patienterna hade god gångförmåga i sitt hem och på jämt underlag (81 % i Malawi och 79 % i Sierra Leone). Däremot hade patienterna svårigheter, eller kunde inte gå alls, på ojämt underlag (41 % i Malawi och 65 % i Sierra Leone), upp och ner för backar (78 % i Malawi och 75 % i Sierra Leone) och i trappor (60 % i Malawi och 66 % i Sierra Leone). Patienterna var ganska nöjda eller mycket nöjda med sina hjälpmedel (medelvärde 3.9 i Malawi och 3.7 i Sierra Leone, maximalt värde 5) och tillhörande service (medelvärde 4.4 i Malawi och 3.7 i Sierra Leone, maximalt värde 5). Patienter i Malawi var signifikant mer nöjda med den ortopedtekniska servicen jämfört med patienterna i Sierra Leone ($p < 0.001$). Samtidigt som många problem rapporterades (418 kommentarer i Malawi och 886 i Sierra Leone). Ungefär hälften av patienterna uppgav att de inte hade tillgången till ortopedteknisk service (71 % i Malawi och 40 % i Sierra Leone). I förhållande till mobilitet och tillfredsställelse med ortopedteknisk service, hade patienter som använde transfemorala proteser eller knä ankel fot ortos sämre resultat än patienter som använde trans tibiala proteser och ankel fot ortos, i både Malawi och Sierra Leone. I Sierra Leone

hade kvinnor sämre resultat än män. De variabler som påverkade patienttillfredsställelse med både ortoser och proteser för nedre extremiteten var smärta, om hjälpmedlen var hela eller trasiga och behövde repareras, förmåga att gå på ojämnt underlag och förmåga att gå i trappor och stiga in i och ut ur en bil. Tillfredsställelse med ortopedteknisk service var påverkad av om patienterna bodde i Malawi eller Sierra Leone, förmåga att gå på ojämnt underlag och i trappor, om hjälpmedlen var hela eller trasiga och behövde repareras och förmåga att betala för omkostnader relaterade till ortopedteknisk service som transport och boende.

Personalens syn på ortopedteknisk service och utbildning resulterade i fyra gemensamma teman för Sierra Leone och Pakistan: 1) Låg medvetenhet och prioritering av ortopedteknisk service, 2) Svårigheter att hantera särskilda sjukdomstillstånd och problem med material, 3) Behov av ytterligare utbildning och vilja till professionell utveckling och 4) Önskan om förbättringar i ortopedingenjörsutbildning. Två teman var unika för Sierra Leone: 1) Personer med funktionsnedsättning har låg status och 2) Begränsad tillgång till ortopedteknisk service.

Slutsatser

Denna avhandling visar att majoriteten av patienterna hade god rörlighet när de använde sina ortoser och proteser och var ganska nöjda med sina ortoser och proteser i Malawi och Sierra Leone. Samtidigt rapporterade en tredjedel av patienterna att de alltid eller ofta upplevde smärta. Mer än hälften av patienterna rapporterade att de upplevde svårigheter att gå på ojämna underlag, och i trappor med sina proteser och ortoser, dessa variabler visade sig också påverka patienttillfredsställelsen med hjälpmedlen negativt. Mer än hälften av proteserna och ortoserna var i behov av reparation, vilket också påverkade patienttillfredsställelsen negativt. Tillfredsställelsen med den ortopedtekniska servicen var påverkad av i vilket land patienterna fått servicen, i Malawi var de mycket nöjda medan patienter i Sierra Leone var ganska nöjda. Tillgång till reparationer och uppföljning var viktiga för patienterna och bör beaktas av ortopedteknisk personal och beslutsfattare för rehabilitering. Kvinnor i Sierra Leone hade sämre resultat jämfört med män

för både personlig rörlighet och tillfredsställelse med hjälpmedel och service.

De intervjuade ortopedteknikerna/-ingenjörerna upplevde oförmåga att leverera ortopedteknisk service av hög kvalitet. Utbildning av ortopedteknisk personal till en akademisk nivå och möjligheter till vidareutbildning önskades. Låg medvetenhet och prioritet av ortopedteknisk service från regeringen lyftes fram som ett hinder för en effektiv rehabilitering. I Sierra Leone efterfrågades att personer med funktionshinder behöver få möjligheter och stöd att inkluderas i större utsträckning inom familjen, samhället i stort, myndigheter och internationella organisationer. Traditionella föreställningar om orsaker till funktionsnedsättning bidrog till bristfällig tillgänglighet till ortopedteknisk service och effektiv rehabilitering. I Pakistan, kunde ortopedingenjörsutbildningen förbättras genom att ändra programinnehåll, uppgradera lärarnas kunskaper, förbättra tillgången till IT-baserad information och vetenskapliga artiklar samt öka jämställdheten för kvinnor. Sammanfattningsvis så föreligger det fortfarande ett stort behov av att implementera mänskliga rättigheter avseende, rätt till personlig rörlighet och rehabilitering för personer med funktionshinder för att möjliggöra ökad delaktighet i samhället, i Malawi, Sierra Leone och Pakistan.

Rekommendationer

Resultatet av de studier som ingår i denna avhandling kan användas vid fortsatt tillhandahållande av ortopedteknisk service i Malawi, Sierra Leone och Pakistan. Lågkostnads benprotesers och benortosers design och tillverkning behöver förbättras i både Malawi och Sierra Leone. Det finns också behov av att göra material mer tillgängligt för tillverkning av proteser och ortoser. Fokus för förbättringar av ortopedtekniska hjälpmedel bör riktas mot ökad förmåga att gå på ojämna underlag, i backar och i trappor samt mot att öka patienternas förmåga att kunna gå längre sträckor utan att uppleva smärta och få sår. Förbättringarna skulle kunna åstadkommas genom ökad eller simulerad ökning av fotledens rörelseomfång, optimalt dimensionerade och mer noggrann dynamisk inställning av benortoser och benproteser. För att öka patienternas tillfredsställelse, behöver uppmärksamhet riktas mot att ökad uppföljning av hjälpmedel och ökad tillgång till reparationer. Det

behövs ekonomiskt stöd till patienter för att de ska kunna betala för transport med kollektivtrafik till rehabiliteringscentren. Interventioner riktade speciellt till kvinnor och ortospatienter bör genomföras för att minska diskriminering av dessa grupper. Både traditionella föreställningar om orsakerna till funktionshinder och samhällets attityder måste ändras i Sierra Leone, för att inkludera människor med funktionshinder och tillämpa mänskliga rättigheter. För att tillhandahålla rehabilitering behövs ett fortsatt stöd från internationella organisationer. För mer ändamålsenlig och effektiv rehabilitering i Sierra Leone och Pakistan, fanns det behov av ett ökat antal utbildade ortopedingenjörer. Dessutom behövs en större andel ortopedingenjörer med akademisk utbildning och möjligheter till vidareutbildning. Innehållet i ortopedingenjörutbildningen i Pakistan bör förändras och lärarnas kunskaper bör uppgraderas. Tillgången till information för studenter bör även förbättras. För att underlätta tillgång till ortopedteknisk service för kvinnliga patienter i Pakistan, måste Pakistan Institute of Prosthetics and Orthotics Science fortsätta att utbilda kvinnliga ortopedingenjörer, men också ge kvinnliga studenter samma förutsättningar och möjligheter som manliga studenter under sin utbildning. Det behövde också skapas möjligheter till kompetensutveckling för ortopedingenjörer i Pakistan. För att implementera Förenta Nationernas konvention om rättigheter för personer med funktionsnedsättning behöver tillgången av ortopedteknisk service öka i omfattning i utvecklingsländer. Många personer med funktionshinder som skulle kunna få öka personlig rörlighet med hjälp av ortopedtekniska hjälpmedel har ännu inte fått någon ortopedteknisk service.

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