SCI-U: e-learning for patient education in spinal cord injury rehabilitation Background and development process

John D. Shepherd[1], Karla M. Badger-Brown[2], Matthew S. Legassic[3], Saagar Walia[3], Dalton L. Wolfe[3]

[1]Rehabilitation Engineering Laboratory, Toronto Rehabilitation Institute/University Health Network, Toronto, Ontario; [2]Badger-Brown Medical Communications, Toronto, Ontario; [3]Lawson Health Research Institute, London, Ontario, Canada

E-learning in patient education

E-learning is the application of information technology to education. It has the potential to improve the effectiveness and reach of education initiatives while reducing costs. E-learning has been used as an effective tool for educational delivery in corporate and healthcare environments. In corporate settings, e-learning has been widely adopted for staff training. In healthcare, e-learning is well established as a sound approach for medical education (Chumley-Jones et al., 2002), and is also used in staff training, particularly for compliance-related topics. In patient education, applications of e-learning are more commonly found in larger disease populations. Studies have demonstrated improved outcomes in both diabetes and breast cancer patients (Austin Boren et al., 2006; Gibbons et al., 2009). By bringing information to the patient at the place and time of their choosing, e-learning has the potential to broaden the reach of existing services and is a promising intervention for outpatients (Chou et al., 2012). It is possible that e-learning could be an effective means of delivering patient education to people with SCI both in the rehab setting and in the community. It is well documented that the internet is a preferred means of accessing information for people with SCI (Letts et al., 2011; Hauber et al., 2002; Burkell et al., 2006; Matter et al., 2009; Edwards et al., 2002; Goodman et al., 2008), and one study demonstrated that a single viewing of an e-learning program on pressure ulcer prevention can improve knowledge (Brace et al, 2010).

E-learning can be used to create engaging learning experiences. The use of multiple media can lead to higher perceived usefulness and improved user concentration (Liu et al., 2009). Additionally, presentations combining text and spoken word are more highly valued by users than those containing only text (Hoffman et al., 2011; Heinrich et al., 2012).

Many SCI rehabilitation programs offer print-based resources and classes, but these both have important limitations (Hoffman et al., 2011). E-learning offers the possibility of educational interventions that are more engaging and effective than print resources, and more widely accessible than classes. Adult learners often have a preference for digital media (Smith-Stoner et al., 2003), and e-learning presentations can be tailored to fit their attention span and visual orientation. E-learning gives learners the ability to control the experience (Ruiz et al., 2007). This interactivity enhances learner engagement and improves learning effectiveness (Zhang et al., 2006).

Designing e-learning interventions

When designing educational interventions that target adult SCI patients, it is important to be informed by adult learning theory (May et al., 2006). Autonomy is a key characteristic of adult learners, and patient education programs must enhance patient autonomy and empowerment in order to facilitate self-directed care (Kelly et al., 2009; Wolfe et al., 2004). This means creating learning experiences that can be self-directed, which is consistent with the development of self-management skills. Different patients have different learning styles, and require appropriate learning strategies (Chase, 2001; Schubart et al., 2008); therefore, the design of education interventions must take into account the differences among learners and engage more than one learning style.

The changing needs of patients across different settings require a variety of methods and messengers, e.g., different media and modes of instruction (Letts et al., 2011). Rather than a single mode of instruction or an uncoordinated mix of methods, the use of multiple methods in structured format has been shown to enhance the effectiveness of patient education (Cooper et al., 2001). For the purposes of SCI rehabilitation, a blended model of instruction is the best option, combining e-learning and other resources with in-person instruction (Zhang et al., 2006). One user requirement is of particular note: patients want to see real depictions of peers in educational programs rather than actors or healthcare professionals, as the latter lack credibility (Barnes et al., 2011). A study of YouTube videos designed to support self-management in SCI showed that viewers found content more accessible when they were able to view a peer doing the task they wished to accomplish (Libin et al., 2011).

Methods

SCI-U was conceived of from the outset as a collaboration given the need to engage participants from across the continuum of care. Partnerships were formed with healthcare organizations providing inpatient SCI rehabilitation in Ontario (Toronto Rehab, now part of University Health Network) and Alberta (Glenrose and Foothills Hospitals). These organizations agreed to make an in-kind contribution of the time and expertise of their clinical staff, who participated in content development working groups. These partners also subsequently supported the usability testing and evaluation of the courses.

In order to access expertise on community integration, we partnered with the Canadian Paraplegic Association Ontario (CPA Ontario), a community service organization serving people living with SCI. Community service workers participated in the working groups, as did some peer support staff (who are typically people with SCI). In addition, this organization helped identify people with SCI for recruitment as content working group members (to contribute their expertise about living with SCI), video presenters and testimonial subjects.

Finally, we partnered with the Lawson Health Research Institute in London, Ontario for the evaluation component of the project, focusing on the first three courses.

Design

The target audience for the courses is people who live with SCI, particularly in the first 1-2 years after injury. There are also several secondary audiences who could benefit from the courses: family members, caregivers and health care professionals. The goal was to support self-management by providing information and developing problem-solving skills.

A needs assessment was performed in order to inform planning for several patient education initiatives including SCI-U. Eighty-three consumers and 99 clinicians and staff from Toronto Rehab and CPA Ontario participated in the survey. Common issues and themes were identified, and this informed the choice of topics for SCI-U courses.

To help publicize the project and encourage uptake, a brand was developed, including a name, a logo and a motto ("For healthy living"). The program was called Spinal Cord Injury University, or SCI-U.

A rapid e-learning authoring application called Articulate was used to produce the courses. One benefit of courses produced with Articulate is the clean, attractive, professional-looking user interface that frames the content on the screen and allows the user to navigate and control the courses. The choice was made to allow (indeed, encourage) users to navigate freely within the courses, rather than forcing them to view the content in a prescribed sequence.

The need to provide visual representations of key concepts was addressed by developing a library of more than 200 icons, using symbolic or stylized representations. The icons can be used to designate complicated terms ("autonomic dysreflexia" is represented by a spiking blood pressure gauge) or sensitive issues ("bowel accident" is indicated by a large exclamation point superimposed on a stylized pair of buttocks). These icons are useful for visual reinforcement and way finding within the courses.

Development process

The SCI-U courses were produced using a four-step development process as shown in Figure 1: content specification; content development; production and population; and finally, review and revision. Developing multimedia education resources is complex, time-consuming and expensive, and requires the coordination of many stakeholders (Elwyn et al., 2011; Hawthorne et al., 2009). Typically, the expertise of varied disciplines is required, from medical research and script writing to instructional design and video production (Ruiz et al., 2007). The development process was designed to facilitate the collaboration of these different contributors.

The project was governed by a steering committee with senior-level representatives of the partner organizations who met initially to agree on resource commitments and choose course topics. The day-to-day work of the project was coordinated by a project team including project staff (lead, project manager and art director) and representatives from key partner organizations. The project team met on a weekly basis throughout the project, over a period of 12 months.

Content development was undertaken by working groups, one for each course, comprising subject-matter experts (SMEs) of various kinds: researchers, clinical and community service staff and consumers. Project team members led the working group

meetings and facilitated collaboration between working group members. Teams met concurrently on-site at the TRI/UHN Lyndhurst Centre (where rehabilitation and community service professionals are co-located) and virtually, using a web conferencing service to permit cross-country participation.

Multimedia production and population of multimedia assets into the finished courses was undertaken by the project team, engaging the skills of specialists as required (video camera and teleprompter, postproduction, etc). Video presenters were selected and coached, then filmed as they read the script from a teleprompter (essential because of the long, detailed script).

Review and revision was the last stage of the development process and incorporated quality control, usability testing and medical review.

Testing and improvement

Course development incorporated continuous testing at all stages. During content development, the use of a wiki-based collective authoring application (PBWorks) enabled working group members to respond to each others' contributions as the script was in development. At the outset and several times during the production and population phases, design options were evaluated by team members and project participants using rapid prototyping.

A beta version of the first course (containing the first section and a few quiz questions and tabs) was produced for early-stage usability testing, looking in particular at issues of accessibility and interface design with a person with high-level tetraplegia, and ease of understanding with a non-native English speaker.

Each course underwent medical review twice during the development process. Before shooting the presenter video, each script was reviewed to ensure accuracy, conformity with best evidence and comprehensiveness. A second round of medical review followed the production of each course, focusing in particular on the illustrations, photos and other visual elements.

Results

By using the development process shown in Figure 1, the project team was able to coordinate the activities of multiple participants to create five courses (the first three were evaluated). The first, called "SCI and You," is an introduction to the physical and emotional effects of SCI and an orientation to the rehabilitation process. The next three (called "Bladder," "Bowel" and "Skin") cover important aspects of body function and self-care. The last course ("Nutrition") gives practical information on healthy eating to prevent the secondary consequences of SCI.

Each course contains approximately 15 "slides" arranged into 3 sections. Each slide covers a specific issue, and features a video presenter who delivers the text. At the same time, visual elements (illustrations, photos and animations) illustrate and reinforce the material, while a bullet-point summary highlights key points from the spoken script. Slides typically last from 30 seconds to 2 minutes.

In addition to the didactic material contained in the slides, each course includes a number of tabs, which provide detailed information users may want to refer to (a word

list, a recipe video or a how-to guide for a self-care activity like digital stimulation). Every course contains a word list tab, which opens an illustrated searchable glossary of key terms. Additionally, all slides have a searchable text of the presentation script in the "Notes" section.

Following each section is a quiz, designed to recapitulate important material and reinforce learning, rather than evaluate it.

The material in each course is delivered by video presenters, who are all people living with SCI (each section has a different presenter); this enhances credibility. Special efforts were made to select video presenters and testimonial subjects who reflect the diversity found in the SCI community, with respect to injury level and time since injury, as well as other demographic characteristics (age, sex, cultural background). In addition to the video presenters, there is a video host for SCI-U overall: a professional TV journalist and presenter who introduces and summarizes each course, and helps users navigate between parts of the course.

The SCI-U courses are very content-rich and media-rich. Each course contains more than 45 minutes of original audiovisual content, with hundreds of illustrations, animations, photos and videos. The large number of media assets helps make the courses engaging and visually appealing.

The extensive use of custom-developed illustrations and animations makes it possible to depict things that would be too costly or impossible to film; they can show cutaway views, blowups and other representations that are useful when showing anatomical features. Illustrations and animations can be made as explicit as is required for educational purposes while remaining tasteful and pleasant to view.

Another important feature of each course is a set of 25 "testimonials;" video clips running for about 2-3 minutes each in which people living with SCI discuss their real-world experiences in a way that reinforces the points covered in the presentation. Each course features 3-5 testimonials, which discuss particular topics and are placed immediately following the slides where those topics are introduced.

Discussion

The aim of this project was to pilot the development of an online patient education resource. This involved the design both of the online courses themselves and of the process used to develop them. The basic approach was to enlist an instructional method (e-learning) in common use in another context (employee/staff training) and apply it to the requirements of patient education in SCI rehabilitation. In so doing, we were able to benefit from the use of a relatively inexpensive and commonly used software application (Articulate) designed for use in the creation of e-learning resources. We were also able to adopt certain practices in common use in commercial e-learning (such as storyboarding).

For almost all participants, this was a new and unusual kind of project. There was a significant amount of learning by doing, meaning that progress was initially slow but that there were significant gains in productivity as the team moved through the process.

Although it is typical for the production of online patient education resources to be outsourced (to a multimedia agency, for example), we found it was very helpful to have

all of the disciplines involved in each stage right from the beginning, with the project team coordinating. There were many occasions where subject matter experts were able to work directly with the production team to ensure that visual details (anatomy, mobility devices) were accurately rendered. By guiding the process from start to finish, the project team was able to ensure that all aspects of the courses (language, design, images, usability) were aligned to create an effective learning experience.

Wherever possible, evidence-based guidelines were used as the basis for script development. The content development process was made more challenging by the need to include a great deal of information that goes beyond what is covered by guidelines. Within this domain of tacit knowledge, the role of the content working groups was to provide informed experience from a number of different perspectives. Across the board, working group members were enthusiastic in their participation. As rehabilitation professionals and patients, they were able to see the value in this kind of resource and were excited by the opportunity to participate in an innovative venture. The extensive participation of persons with SCI in all aspects of development was a key principle from the outset. This involvement was necessary to generate the content, in that people living with SCI are clearly subject matter experts with respect to living with SCI. It also helped shape the language and appearance of the courses. Having persons with SCI involved at all stages also provided a continuous stream of user feedback. It helped ground the courses in the reality of community (rather than hospital) life; real-world examples and testimonials helped to illustrate lessons that were considered relevant by evaluation participants.

Great care was taken to ensure that the courses were attractive and appealing, and that they provide a positive, realistic image of life with SCI. Illustrations and images helped to convey important facts and ideas; they also helped positively re-frame images of disability.

Overall, the work undertaken through the development process appears to have resulted in the creation of a credible, relevant and user-friendly resource that will be effective for persons with SCI to better understand the consequences of their injury and self-manage their condition. The preliminary evaluation results are encouraging and will be used to inform future development of these and additional courses.

Conclusion

The courses developed for SCI-U show the potential for online patient education. Preliminary evaluation indicates that they are appreciated by end-users; further evaluation will focus on knowledge acquisition and retention. The collaboration required to develop content was essential, and was facilitated by the use of IT tools. In particular, the extensive participation of patients was crucial.

SCI-U demonstrates a promising approach; further research will need to study how to integrate this kind of resource into clinical practice and how to drive consumer uptake. This is a domain where technological innovation is currently happening at a rapid pace, opening up new possibilities; future work will need to be attuned to these developments.

REFERENCES

Austin Boren S, Gunlock TL, Krishna S, Kramer TC. Computer-aided diabetes education: a synthesis of randomized controlled trials. AMIA Annu Symp Proc. 2006:51-5.

Barnes E, Simpson S, Griffiths E, Hood K, Craddock N, Smith DJ. Developing an online psychoeducation package for bipolar disorder. J Ment Health. 2011;20(1):21-31.

Brace JA, Schubart JR. A prospective evaluation of a pressure ulcer prevention and management E-Learning Program for adults with spinal cord injury. Ostomy Wound Manage. 2010;56(8):40-50.

Burkell JA, Wolfe DL, Potter PJ, Jutai JW. Information needs and information sources of individuals living with spinal cord injury. Health Inf Libr J. 2006;23(4):257-65.

Chase TM. Learning styles and teaching strategies: enhancing the patient education experience. SCI Nurs. 2001;18(3):138-41.

Chou HK, Lin IC, Woung LC, Tsai MT. An empirical study on outpatients' health education needs and the effectiveness of e-learning. Health Promot Pract. 2012;13(1):133-9.

Chumley-Jones HS, Dobbie A, Alford CL. Web-based learning: sound educational method or hype? A review of the evaluation literature. Acad Med. 2002;77(10 Suppl):S86-93.

Cooper H, Booth K, Fear S, Gill G. Chronic disease patient education: lessons from meta-analyses. Patient Educ Couns. 2001;44:107-17.

Edwards L, Krassioukov A, Fehlings MG. Importance of access to research information among individuals with spinal cord injury: results of an evidence-based questionnaire. Spinal Cord. 2002;40(10):529-35.

Elwyn G, Kreuwel I, Durand MA, et al. How to develop web-based decision support interventions for patients: a process map. Patient Educ Couns. 2011;82(2):260-5.

Gibbons MC, Wilson RF, Samal L, et al. Impact of consumer health informatics applications. Evid Rep Technol Assess (Full Rep). 2009;(188):1-546.

Goodman N, Jette AM, Houlihan B, Williams S. Computer and internet use by persons after traumatic spinal cord injury. Arch Phys Med Rehabil. 2008;89(8):1492-8.

Hauber RP, Vesmarovich S, Dufour L. The use of computers and the Internet as a source of health information for people with disabilities. Rehabil Nurs. 2002;27(4):142-5.

Hawthorne K, Prout H, Kinnersley P, Houston H. Evaluation of different delivery modes of an interactive e-learning programme for teaching cultural diversity. Patient Educ Couns. 2009;74(1):5-11.

Heinrich E, de Nooijer J, Schaper NC, Schoonus-Spit MH, Janssen MA, de Vries NK. Evaluation of the web-based Diabetes Interactive Education Programme (DIEP) for patients with type 2 diabetes. Patient Educ Couns. 2012;86(2):172-8.

Hoffman J, Salzman C, Garbaccio C, Burns SP, Crane D, Bombardier C. Use of on-demand video to provide patient education on spinal cord injury. J Spinal Cord Med. 2011;34(4):404-9.

Kelly M, Lyng C, McGrath M, Cannon G. A multi-method study to determine the effectiveness of, and student attitudes to, online instructional videos for teaching clinical nursing skills. Nurse Educ Today. 2009;29(3):292-300.

Letts L, Martin Ginis KA, Faulkner G, Colquhoun H, Levac D, Gorczynski P. Preferred methods and messengers for delivering physical activity information to people with spinal cord injury: a focus group study. Rehabil Psychol. 2011;56(2):128-37.

Libin A, Schladen M, Ljungberg I, et al. YouTube as an on-line disability self-management tool in persons with spinal cord injury. Top Spinal Cord Inj Rehabil. 2011;16(3):84-92.

Liu S, Liao H, Pratt J. Impact of media richness and flow on e-learning technology acceptance. Computers Educ. 2009;52:599-607.

May L, Day R, Warren S. Evaluation of patient education in spinal cord injury rehabilitation: knowledge, problem-solving and perceived importance. Disabil Rehabil. 2006;28(7):405-13.

Matter B, Feinberg M, Schomer K, Harniss M, Brown P, Johnson K. Information needs of persons with spinal cord injuries. J Spinal Cord Med. 2009;32(5):545-54.

Ruiz JG, Teasdale TA, Hajjar I, Shaughnessy M, Mintzer MJ. The Consortium of E-Learning in Geriatrics Instruction. J Am Geriatr Soc. 2007;55(3):458-63.

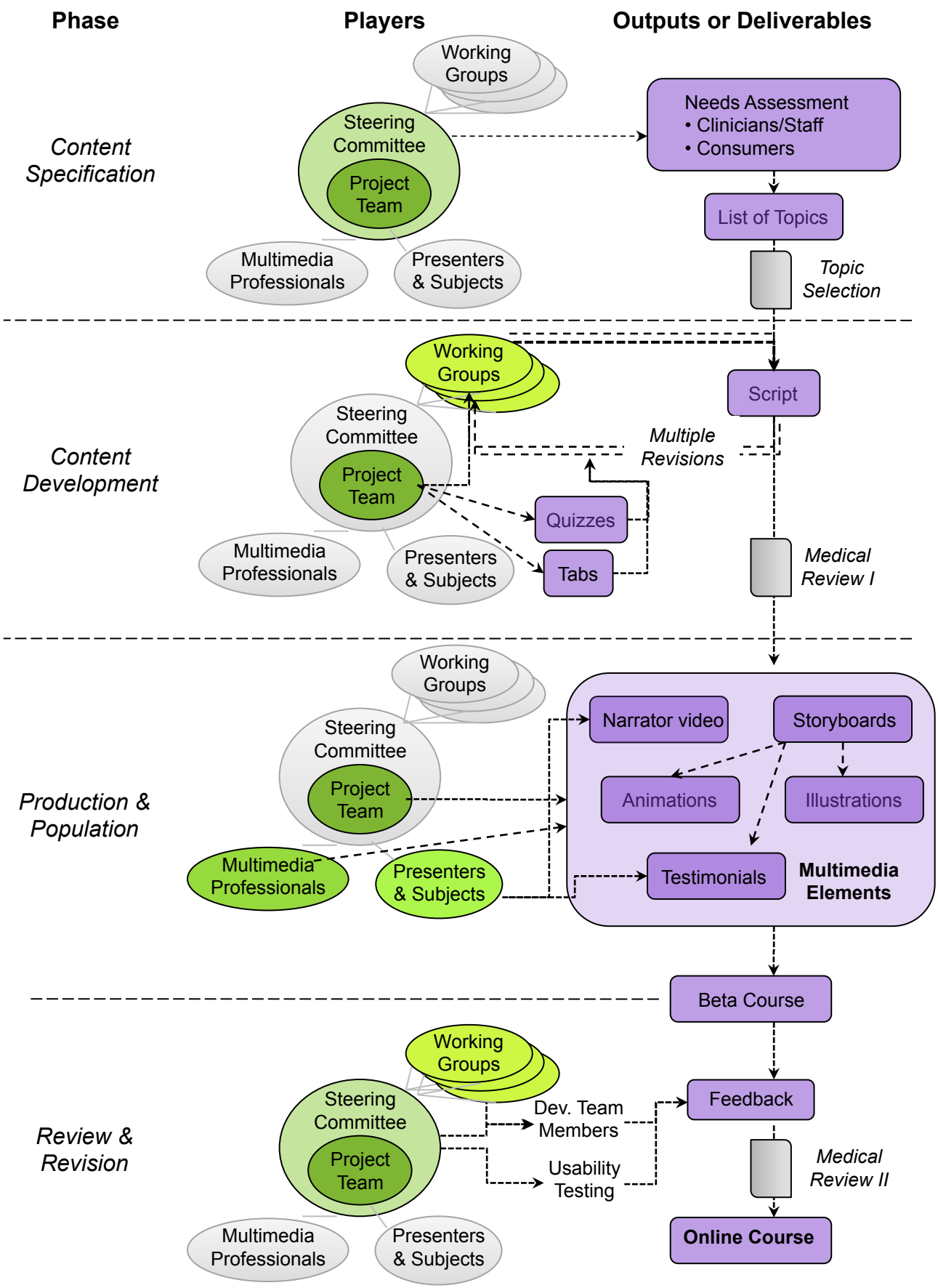
Schubart JR, Hilgart M, Lyder C. Pressure ulcer prevention and management in spinal cord-injured adults: analysis of educational needs. Adv Skin Wound Care. 2008;21(7):322-9.

Smith-Stoner M, Willer A. Video streaming in nursing education: bringing life to online education. Nurse Educ. 2003;28(2):66-70.

Wolfe DL, Potter PJ, Sequeira KAJ. Overcoming challenges: The role of rehabilitation in educating individuals with SCI to reduce secondary conditions. Top Spinal Cord Inj Rehabil. 2004;10(1):41-50.

Zhang D, Zhou L, Briggs R, Nunamaker J. Instructional video in e-learning: Assessing the impact of interactive video on learning effectiveness. Inf Manage. 2006;43:15-27.

FIGURE 1


Phase
Players
Outputs or Deliverables
Content Specification
Working Groups
Steering Committee
Project Team
Multimedia Professionals
Presenters & Subjects
Needs Assessment
• Clinicians/Staff
• Consumers
List of Topics
Topic Selection
Content Development
Working Groups
Steering Committee
Project Team
Multimedia Professionals
Presenters & Subjects
Script
Multiple Revisions
Quizzes
Tabs
Medical Review I
Production & Population
Working Groups
Steering Committee
Project Team
Multimedia Professionals
Presenters & Subjects
Narrator video
Storyboards
Animations
Illustrations
Testimonials
Multimedia Elements
Beta Course
Review & Revision
Working Groups
Steering Committee
Project Team
Multimedia Professionals
Presenters & Subjects
Dev. Team Members
Usability Testing
Feedback
Medical Review II
Online Course