Preface

INTRODUCTION

A traditional community is a place for people who share the same interests and concerns to meet to cooperate and to satisfy each other’s needs. E-communities, communities mediated by ICT and the Internet, are used in many areas and for different purposes. Some are open for anyone to join, and some are closed and can only be accessed by an invited group. A common interest and concern for each other is the glue that holds the community together; it should be able to support a sense of togetherness among the community members. It can also be regarded as a virtually social network useful for empathetic support, information sharing, and problem solving.

A certain type of e-communities is used by people who want to discuss health issues with others who share similar health concerns. These e-health communities have become popular arenas for support and sharing of experience, knowledge, and advice among patients and citizens. This group of users has grown rapidly in number and constitutes a large and increasing group on the Internet today. E-health communities are used on a day-to-day basis by people who want to help each other cope with different health conditions and learn together about health-related issues and behaviors. E-health communities create online self-help groups. They exist in many different health areas, from severe physical and mental disorders, such as cancer and depression, to aftercare for patients who are about to return to society, and lifestyle problems such as bad eating and exercising habits, smoking, and stressful lives, that is, lifestyles considered causing health risks to people. There are also self-help systems customized for different age groups, such as children and elderly, and their special conditions and needs.

The growth of e-health communities has contributed to a shift of focus: from healthcare and healthcare givers being the only source of help for most patients, to a situation where patients and citizens take active part in the health and recovery of each other. This has also opened up for patients and citizens to fill a gap: as a group, they can ask for and give support 24 hours a day, 7 days a week. It allows for patients and citizens with health concerns to become both producers and consumers of health information and support. This new active role on the Internet is also called “prosumer,” which illustrates the blur between the two previously separate roles. Through the online self-help groups, patients as well as citizens have shown to be more empowered. The Internet and the more available health information and conversations on health issues have even brought empowerment to minority and marginalized groups in the society, such as elderly people. Through the new opportunities, patients can more easily develop confidence to interact effectively with healthcare providers.

The e-health communities help people share experiences, learn together, and provide advice on how to cope with various health problems. In these e-health communities, different types of relationships between participants are developed. There are relationships between people who know each other well,
who have access to similar information, common values and approaches, and who provide social and emotional support and self-disclosure reports. There are also relationships characterized by less frequent communication between people who do not know each other well. The latter is also important in order to let the e-health community experience new approaches and opposing ideas.

Although the widespread use of Internet health services and e-health communities has created a lot of new possibilities, they do not automatically lead to certain positive health outcomes or to the public being better informed. It is not given in what ways they affect our health and well-being, and our social or work life. Instead, consequences are highly dependent on contexts. The e-health communities can be utilized in many ways and lead to various social and health outcomes. Community members have different concerns; they communicate on different issues, in different ways, and different community cultures evolve.

In this new world of increased usage of e-health communities, there is a need to discuss different ways of designing and using these systems for communication and learning in groups. There is also a need to systematically evaluate them in terms of learning opportunities, behavioral changes, and impacts on health and well-being.

**OBJECTIVE OF THE BOOK**

This book offers relevant theoretical frameworks and the latest empirical research findings in the area of e-health communities and online self-help groups. It aims to increase knowledge and understanding of applications and usage of e-health communities for different groups of people who struggle with health disorders, disabilities, lifestyle issues, and other health concerns. The book presents different e-health community settings and aspects, observations of community usage and effects, policy issues, and complementing ways to study and measure effectiveness.

The book addresses health issues that may be of concern to many people. The target audience of this book is researchers and advanced level students in social and health informatics, designers of e-health platforms, and clinical health professionals, such as physicians, dieticians, physiotherapists, and district nurses. It can also be useful for patient interest groups. Moreover, the book provides insights that may support executives concerned with making IT strategies for healthcare.

**STRUCTURE OF THE BOOK**

The book is organized into five sections. The first section is dedicated to e-health communities for different age groups; chapters 1, 2, 3, and 4 are included in this section. This section addresses certain age-related topics for children who are affected by severe illnesses: their relations to peers and siblings, medication, and school work, for example. This section is also concerned with elderly people: their specific needs and concerns, such as changing social lives and the need for continuous mental training. The second section of the book, chapters 5, 6, 7, 8, and 9, is concerned with different medical conditions, lifestyle issues, and other health issues. The chapters address e-health communities for people who have been sexually abused, for people with cancer and HIV, with eating disorders and stressful lives. The third section of the book includes chapters 10 and 11. The chapters of this section discuss pedagogical and educational aspects of e-health communities. The fourth section of the book, chapters 12, 13, and 14, deals with
issues related to digital inclusion and usability. The fifth section introduces the reader to health policy issues; chapters 15, 16 and 17 address this topic. Below, each chapter is introduced with a few words.

Chapter 1 describes a virtual world for children with critical medical conditions. The chapter guides the reader through two experiences: one with post-transplant pediatric patients and another with pediatric cancer patients. In the first experience, issues of medical adherence and school transition are addressed, and the second experience addresses issues related to sustainable friendship and levels of hope through a virtual summer camp for young patients and their siblings. The virtual world was designed based on a theoretical framework – Positive Technological Development. The designed virtual world offers a range of online activities, such as content creation, collaboration and caring, communication, and community-building. The chapter shows pediatric patients as active and creative participants in the virtual world.

Chapter 2 addresses a great health challenge: treatment of childhood obesity. The chapter discusses how to use e-health technologies to improve treatment adherence, promote mechanisms of self-control in patients, maintain weight loss achievements, and prevent relapses by establishing healthy lifestyles. The chapter presents an e-health system that addresses these weight loss treatment issues. The system consists of three complementary applications: clinical support, home support, and mobile support. The chapter illustrates the system tools, such as a game designed to improve the children’s nutrition knowledge, another game to improve their daily behaviors, and devices to record physical habits and physiological responses.

Chapter 3 provides an overview of Internet-based chronic disease self-management treatment programs for children and youth. Promoting self-management for adolescents with chronic diseases requires an understanding of how children with these diseases gradually develop the ability to take the lead from being reliant on parents and caregivers. The chapter defines and describes the theories, processes, and content elements Internet-based self-management programs are based on. It also presents experiences from developing and testing a self-management program for young people with arthritis called “Teens Taking Charge: Managing Arthritis Online.” Practical tips for program development and evaluation in this area are discussed.

Chapter 4 addresses how to use ICT for promoting well-being among elderly people. It targets the needs of the elderly population in general, such as the need to break isolation and increase social activities, sustain family companionship, and to ease anxiety. The chapter presents an IT-system in which elderly people, family and friends, and also health professionals, interact. The system has different levels of action: therapeutic, playful, and evaluative. It offers resources that enhance elderly users’ social networks, and help them stay in contact with family and friends online, as well as enhance their learning, leisure and training of positive emotions. The platform also allows health practitioners to continuously monitor emotional states of the elderly and offers various clinical resources and therapeutic activities.

Chapter 5 deals with online communities and the social networks of cancer patients. It presents the results of a study of determinants and effects of online communities on the development of social relationships among cancer patients. Determinants for formation of virtual relationships are discussed. Socio-demographical characteristics of patients, type of cancer, Internet usage behavior, and perception of advantages and disadvantages are analyzed. The chapter also outlines some recommendations for patients who use online communities and for providers who administrate them.

Chapter 6 addresses social support as an important coping strategy for survivors of sexual violence. The experience of sexual violence is most traumatic and stressful, and the ones who try to recover from it need social support. The chapter presents the results from a content analysis of an online support group for survivors of sexual violence. The online conversations targeted issues such as appraisal of the situation,
the handling of feelings, understanding and sympathy, and guidance to enhance faith in one’s abilities. The messages in the studied conversations were categorized according to five different types of support: information support, tangible assistance, esteem support, network support, and emotional support.

Chapter 7 explores blogging as a tool for coping with a lifelong and highly stigmatized disease. The chapter offers insights into the social and health concerns of people living with HIV. It presents results from a study of six HIV-positive individuals’ blogs. The blogs are discussed from different perspectives: social interaction, information sharing, self-expression, and social commentary, and illustrative quotes from the blogs are shown.

Chapter 8 challenges the assumption that a small set of stored answers are enough to answer most of the questions in a particular topical area. The chapter presents results from a study of an online service for questions on eating disorders. It offers insights into different types of questions on anorexia nervosa, bulimia nervosa, binge eating disorder and/or obesity, and other or unspecified eating disorders. The results show that the variety of questions is large, and that to provide satisfactory answers, humans are needed.

Chapter 9 addresses holistic system design for online self-help groups. The chapter presents a web-based self-help system for stress management that combines knowledge and experiences of health experts and peers. The system offers research findings, real-life stories, practical exercises and interaction with health experts and peers. The system is based on the active and self-driven participation of people with stress symptoms, and the chapter suggests a model for system evaluation that includes measures related both to the health status of users and to their use of the system, such as patterns of conversations, contents of messages, and the use of systems services.

Chapter 10 addresses blending professional and experiential knowledge in online self-help groups. The chapter offers a theoretical overview of learning processes and self-help groups in a learning context. It also presents and analyzes practical aspects from the course, “Living a healthier life – online,” a course that was transformed from face-to-face to online as part of a design-based research project. The chapter argues that online self-help settings need to be facilitated in a firmer manner than face-to-face, and that socialization and overall assignments are two crucial elements in facilitating online self-help initiatives in a learning context.

Chapter 11 addresses motivation and engagement in online self-help groups. Based on theoretical frameworks and practical experiences, the chapter identifies five factors suggested as enablers or constrainers of engagement: synchronicity, identification, specified diagnosis, organizational trust, and accessibility. The chapter applies these five factors to discuss participation in Skype-based self-help groups.

Chapter 12 addresses challenges of digital inclusion. Elderly and disabled people constitute a group of users who can benefit a lot from accessing e-health services and communities, but at the same this group is sensitive to the design of the e-health systems. This is a dilemma that needs further attention. Inclusive design aims to produce solutions available and usable to as many as possible of the target audience. The chapter shows how user-centered and inclusive design is to be used as a basis on which successful e-health systems can be developed and implemented. It also investigates different aspects of online social networks and social connectedness.

Chapter 13 deals with e-health literacy in the context of online health communities. There are different health literacy skills and knowledge needed to understand and communicate effectively about health issues. Not only reading, writing, and communicative skills are needed to function well, but also the ability to critically analyze information, apply information to personal situations, understand health issues as social problems, and recognize cultural differences, for example. The chapter offers a theoretical overview of different health and e-health literacy domains. It also uses the online weight-loss
community, the Biggest Loser League, as a case study. A content analysis of the community posts was conducted to examine domains of health literacy.

Chapter 14 addresses design requirements for usable e-health communities in mobile devices. This chapter proposes a set of basic usability requirements specifically oriented to mobile interfaces for blog-based instant messaging e-health communities. The usability requirements are related to interface dimensions, user representation, navigation, adaptability, and turns in online conversations, for example. The chapter also presents an e-health community interface prototype for mobile device based on the proposed requirements.

Chapter 15 addresses the use of digital technologies to engage health citizen communities in health policy. Patient organizations, or citizen health organizations, are engaging with healthcare professionals and government decision-makers in order to advance their interests. The chapter investigates three different models for organizing citizen participation and the role of ICT and the Internet to facilitate and enable engagement on a day-to-day basis. The models are represented by three citizen health organizations; their ways of using ICT and the internet to create practices and e-health communities are examined.

Chapter 16 introduces e-health from a European perspective; it presents insights into the European policy work and discusses drives and barriers towards a Europe with “patient-friendly” healthcare services. The chapter argues that there is a need for political awareness and commitment to take advantage of new technology and to have e-health change the everyday practices of healthcare.

Chapter 17 addresses the development of online communities to support drug policy knowledge exchange and to bridge between academics and policy-makers. It presents results from a study of three drug policy groups and their different virtual knowledge exchange activities. The chapter offers lessons learned regarding the impacts of conferencing technologies on knowledge exchange drug policy groups, and it presents recommendations on how to conduct successful virtual knowledge exchange meetings based on the findings from the studied groups.

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