Chapter 1.27
Virtual Communities in Health and Social Care

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ABSTRACT

This chapter provides an overview and discussion of virtual communities in health and social care. The available literature indicates that a virtual community in health or social care can be defined as a group of people using telecommunications with the purposes of delivering health care and education, and/or providing support. Such communities cover a wide range of clinical specialties, technologies and stakeholders. Examples include peer-to-peer networks, virtual health care delivery and E-Science research teams. Virtual communities may empower patients and enhance coordination of care services; however, there is not sufficient systematic evidence of the effectiveness of virtual communities on clinical outcomes. When practitioners utilize virtual community tools to communicate with patients or colleagues they have to maximize sociability and usability of this mode of communication, while addressing concerns for privacy and the fear of de-humanizing practice, and the lack of clarity or relevance of current legislative frameworks. Furthermore, the authors discuss in this context ethical, legal considerations and the current status of research in this domain. Ethical challenges including the concepts of identity and deception, privacy and confidentiality and technical issues, such as sociability and usability are introduced and discussed.

INTRODUCTION

Health care is a sector which today experiences a number of pressures, both from inside and outside. The continuing innovation in medicine and health care technologies expands the methods and tools available in health care. Combined with citizen empowerment the demographic changes of an ageing European population stretch the limits of what countries can afford to offer as services within their national health systems.

Governments are confronted by the urgent need to find means to contain the rise in health care expenditure without compromising quality, equity and access. Consequently, new ways to organise and deliver health services are being investigated and experimented with. Public-private partnerships in care delivery are emerging. Citizens and patients are given more responsibility in the management of their own health and chronic illnesses (World Health Organisation, 2002).

As a result of these developments, an important trend throughout Europe and globally is a move towards more involvement of patients or citizens in informed decision making of any choice and responsibility for their own health. The vision behind this work is comprised of two components: new innovative services to the citizens and networking services and care across organisational boundaries. Within such a context, virtual communities, despite their infant stage, have already shown the potential to provide new virtuality in the collaboration and communication-intensive paradigm that progressively emerges.

The Changing Environment

Considering the dynamics in health care, the traditional system model of health care has emphasized hierarchical structures with strict separation of organisational responsibilities within the framework of health care. This hierarchy can be seen through the following points:

- Strict organisational division of responsibilities between primary care (e.g., municipal GP-led health centres) and secondary care (e.g. regional or specialist-led hospitals).
- Geographical separation of patient care responsibility (e.g., within primary and secondary care).
- Separation of duties between different health care professional groups (i.e., physicians and nurses) and specialties as well as separation of patients from the care process.
- Separation between public and private care providers within the different levels.

In the healthcare information and communication technology (ICT) context, these hierarchical divisions can be seen in the implementation and scope of information and communication systems used by care facilitators. Separation is actually amplified when exchange of information is considered. Conventional health ICT systems, supporting overall service provision, are centralized and follow these boundaries closely, while system interoperability is often minimal. Furthermore, direct patient access to electronic patient record information is typically minimal or non-existent. Similarly for professionals, the use of integrated ICT systems and services is restricted to their primary working facility.

This traditional system model faces several challenges and structural changes are unavoidable (Tsiknakis & Saranummi, 2005). For example, aging populations, limited resource allocations, increasing specialization in medicine requiring convenient consultation tools, and trends towards patient and non-physician empowerment drive the system towards the breaking down of strict organizational and other boundaries, i.e. towards process-orientation and ad-hoc networking in the search for better results. As a result we witness a movement towards shared or integrated care in which the single doctor–patient relationship is giv-

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