Web-Based Health Communities for Self-Help Groups

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What is a Community and a Web-Based Community?

- A traditional community is a place for people who share the same interests to meet - to cooperate and to satisfy each other's needs.

- A web-based community uses ICT and the Net to mediate interaction.

- Web-based communities are used in many areas and for different purposes.

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Web-Based Health Communities

- The usage of web-based health communities for sharing experiences, information, advice and support has increased.

- For self-help groups with peers having similar conditions and health concerns.

- Empowerment through self-help groups.

- Some examples

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Virtual Worlds for Children with Medical Conditions

- The "Zora virtual world"

- A social network of peers

- A virtual city

  – To ease school transition and medical adherence for post-transplant patients.

- A virtual summer camp

  – For cancer patients and their siblings to stay connected after a physical summer camp.

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Support Groups for Survivors of Sexual Violence

- Social support as an important coping strategy.

- Anonymity in online support groups allows a combination of personal information, intimacy and discretion.

- Online Support Behaviors
  - Information support
  - Tangible Assistance
  - Esteem Support
  - Network Support
  - Emotional Support

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"The Butler System" for Promoting Wellbeing among Elderly

- "Healthy ageing" and "Active ageing"

- Online e-health platform to promote social networks, communication, entertainment, learning, curiosity and training of positive emotions.

- Different levels of action
  - Assessment Action Level
  - Therapeutic Action Level
  - Playful Action Level

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Preventive Health and Web-Based Communities

- Overweight/obesity, smoking, stressful lives, e.g.

- Changing established bad habits can reduce the risk of getting severe illnesses

- How can web-based communities enable people to learn a new behavior?

Learning through Web-Based Communication

- Web-based communication enables continuous social interaction, learning and support.

- To help each other to learn, we need to understand the situations of others and to adjust our support, advice and own stories.

- The use of language in a social context.

- Learning a new behavior includes also questioning the way we act today.

  – Underlying models, values and beliefs

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Observations of Web-Based Community Communication

- Stored conversations

- Observed unstructured data

- To understand human activity and social interaction

- To detect problems

- Observations are used formatively or summatively

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Categories of Conversations for Learning

➢ **Statements**

➢ **Requests on neutral issues - fact queries**

➢ **Requests on personal issues:**

  ✓ **Setbacks**
    –Personal experiences of recurrent breakdowns

  ✓ **Obstacles**
    –Foreseen difficulties to overcome

  ✓ **Incentives**
    –Motivational factors, induce action or motivate effort

Ex: Frequency of Issues

Type of Issue	Issues on Overweight	Issues on Smoking/alcohol/drugs	Total No.
Fact query	42	38	80 (40%)
Incentive	12	10	22 (11%)
Setback	25	10	35 (18%)
Obstacle	6	17	23 (11%)
Statement	15	25	40 (20%)
Total	100	100	200

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Web-Based Community Interaction

- We can also learn from the ways the community members interact on issues.

    - With confirmation and empathy, experiences and advice, or with opposing perspectives and questioning of ideas.

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Ex: Frequency of Counter-Acts

Online Community	Responses with Opposing Ideas		Responses with Strong Rejections		Responses in Total
Online community on overweight (the Swedish site)	41	20%	3	2%	200
Online community on overweight (the UK site)	18	18%	4	4%	102
Online community on smoking (the Swedish site)	11	6%	0	0%	190
Online community on smoking, alcohol and drug abuse (the UK site)	26	18%	5	3%	146
Total	96	15%	12	2%	638

E-Health to Empower Patients and Citizens

- Exchange of health information, as well as learning and support through interaction

- Citizens and patients offering complementary knowledge and experiences

- Empowering people

- New roles for the healthcare and healthcare providers

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Holistic Approach to E-Health

- Towards integrating different actors, knowledge, conversations and support to a working whole

- Flexible and dynamic web-based systems for both patients/citizens and health professionals

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