

## Cyber-Ribbons: The Influence of Internet Support Groups on Healing From Illness.

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<http://tinyurl.com/mbdwfg>

## What is an Awareness Ribbon?

- A satin ribbon that is folded over and pinned
- Meaning is derived from the color of the ribbon
- Ribbons are worn to demonstrate solidarity with a cause or raise awareness for most known issues such as:
  - Diseases (Breast cancer, AIDS, Alzheimer's)
  - Conditions (Autism, Organ transplantation, Anxiety)
  - Social situations (War, 9/11, VT 4/16)
  - Social Issues (Domestic Violence, Suicide Awareness, Gang prevention, POW/MIA)



## Origins of Awareness Ribbons

- Some say the use of ribbons to support is tied to military use of ribbons for awarding valor
- Others attribute it to the tying of yellow ribbons around trees during the Vietnam War
  - 1973: Tony Orlando and Dawn sang "Tie a Yellow Ribbon Round the Old Oak Tree."
- 1992: Red ribbons began symbolizing AIDS awareness.
  - "The Year of the Ribbon," was declared by the NY Times
- The use of different colored ribbons exploded during the 1990's



<http://tinyurl.com/k3myps5>; <http://tinyurl.com/kbh733>

## American Cancer Society/ Relay for Life Ribbon List

All Cancers Lavender	Gallbladder/Bile Duct Cancer Kelly Green	Ovarian Cancer Teal
Appendix Cancer Amber	Head & Neck Cancer Burgundy/Ivory	Pancreatic Cancer Purple
Bladder Cancer Marigold/Blue/Purple	Kidney Cancer Orange	Prostate Cancer Light Blue
Brain Cancer Grey	Leiomyosarcoma Purple	Sarcoma/Bone Cancer Yellow
Breast Cancer Pink	Leukemia Orange	Stomach Cancer Periwinkle
Carcinoid Cancer Zebra Stripe	Liver Cancer Emerald Green	Testicular Cancer Orchid
Cervical Cancer Teal/White	Lung Cancer White	Thyroid Cancer Teal/Pink/Blue
Childhood Cancer Gold	Lymphoma Lime	Uterine Cancer Peach
Colon Cancer Dark Blue	Melanoma Black	Honors Caregivers Plum
Esophageal Cancer Periwinkle	Multiple Myeloma Burgundy	

Click here for a printable chart of CANCER AWARENESS RIBBON COLORS

<http://preview.tinyurl.com/k3myps5>

## Ribbons and the Internet

- The use of ribbons to demonstrate solidarity or raise awareness occurred around the same time as the Internet became adopted as a norm in the mainstream U.S.
- Internet support groups often use pictures of these ribbons as a symbol for the cause that is being supported
- There are as many different types of Internet support groups as there are ribbons



<http://tinyurl.com/m3ubbnx>, <http://tinyurl.com/mobw9u4>

## Why Are Internet Support Groups Important?

- The same reason that we use ribbons: To raise awareness and bring solidarity
- **Virtual Community Building**
  - This is crucial when illness and disease is the primary concern
  - It is easy to look up symptoms in a basic Internet search and feel panicked
  - Internet Illness Support Groups can help those who are isolated (and who are not) sort through confusing and scary information



<http://tinyurl.com/n864z9>

## Virtual Community Building

- Internet support groups are able to provide support to individuals (and families) who are isolated



<http://tinyurl.com/p3nr3yz>

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## Isolation Can Take Many Forms

- Isolation can take many forms:
  - Geographic
    - Rural
    - Small Communities
  - Physical
  - Socioemotional
  - Consequential
    - Fear
    - Shame
  - Identity
  - Rarity



<http://tinyurl.com/phdl4jy>

## Geographic Isolation



- Living in a rural area can increase the potential for isolation in general
- Health Professional Shortage Areas (HPSA)
  - Designation by the Federal Government
  - Rural areas of the U.S. that have a shortage of primary medical or dental care
  - Specialized medical care is very often nonexistent in these areas
  - Travelling to see a health care professional can be costly
- Along with basic socioemotional support, in these areas in particular, Internet Illness Support Groups can provide people with a vital resource for understanding their illness:
  - What is "normal"
  - What is not normal
  - Is it worth the investment to see a medical professional

<http://tinyurl.com/owmfloq>

## Physical Isolation



- People who do not have the physical ability or means to seek out resources or support for their condition can greatly benefit from Internet Illness Support Groups
- Because people with these issues often depend on others for travel to a health care provider, they often wait to call for help until
- Internet Illness Support Groups can help them ascertain when they must see a medical professional
- They can also provide crucial socioemotional support

<http://tinyurl.com/oeqv3nb>

## Socioemotional Isolation



- When someone has socioemotional reasons for either not leaving their home or visiting a health care professional, Internet Illness Support Groups can be crucial in increasing their wellness
- Intense anxiety
  - Generalized anxiety, post traumatic stress disorder, etc
- Depression
- Grief and bereavement
- Agoraphobia (fear of open spaces)
- Latrophobia (fear of health care professionals)
- Trypanophobia (fear of needles)



<http://tinyurl.com/qtmqzo>; <http://tinyurl.com/nmmwq6w>

## Consequential Isolation



- People with an illness or disease that causes great shame
  - HIV/AIDS
  - Sexually transmitted infections
  - Eating disorders
  - Sexual concerns
  - Prior to Nancy Reagan's admission: Breast Cancer
  - Depression
  - Post Traumatic Stress Disorder
  - Most mental illness
  - Addiction
- This can be coupled with a fear of rejection or judgment
- Side effects of procedures or prescribed substances that are considered embarrassing



<http://tinyurl.com/nmza94d>; <http://tinyurl.com/qmcavm>; <http://tinyurl.com/np9to7q>

## Rarity Isolation

- People with rare illnesses or diseases are especially vulnerable to the socioemotional impact of their condition
- Believing we are the only person experiencing our situation increases fear and stress
- This can increase the impact of physiological issues such as illness and disease
- It is important to know we are not alone and have solidarity
- Internet Illness Support Groups provide a crucial service to people in this situation



This is the ribbon for Male Breast Cancer

<http://tinyurl.com/p4tpour>

## Identity Isolation

- People who are well known in a community, state, or the nation may avoid seeking assistance due to community member or media interest
- This translates to their family members as well
- Public officials
- Religious officiates
- Educators
- Business owners
- Actors
- The medium of the Internet provides the opportunity for anonymity and allows these people to receive support without revealing their identity



Elizabeth Edwards used Internet Illness Support groups for dealing with the loss of her son, the experience of breast cancer, and the infidelity of her husband.

<http://tinyurl.com/ns9n5ft>

## Compound Isolation

- Experiencing more than one form of isolation compounds the suffering that is experienced due to the illness or disease.
- Someone who is geographically isolated and also has the consequential isolation of carrying the diagnosis of the mental illness Schizophrenia has increased needs for support:
  - Assistance in figuring out if/when they should spend resources to seek out health care
  - Assistance and support in understanding what they are feeling as normal/ not normal
  - Support with having a stigmatized mental illness
- The more types of isolation faced by the person, the greater their need for support
- Internet Illness Support Groups are ideally suited for these scenarios



<http://tinyurl.com/lyears>

## The Problem with Internet Support Groups

- We must have access to the Internet
  - This requires a computer and reliable Internet connection
  - Cost
  - Public computers are not always accessible and are not always private
- The Internet allows us to be whomever we want to be
- It is easy to be invisible
- This is a positive for people who need to hide their identity, but a negative for people who isolate themselves as a symptom of their diagnosis
- It is easy to be a bully



<http://tinyurl.com/mx6d4m>; <http://tinyurl.com/kx46ww7>; <http://tinyurl.com/k8fmr53>

## The Problem with Internet Support Groups

- There is some advice that should only come from a medical professional
- Any interaction in Internet Illness Support Groups comes through the biases and worldview of the members
  - It is possible to get bad advice
- It is difficult to conduct accurate research on Internet Support Groups, so our knowledge is not as certain
- STILL: The benefits to these populations often FAR outweigh the risks



<http://tinyurl.com/koesvmh>

Thank you!

References Available Upon Request

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