Breaking the Hepatitis Social Stigma and Disclosing the Hepatitis Status at Workplace/Home: Patient Experience

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Outline of the Presentation

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Objective

The aim of this presentation is to tell you my experience as a Hepatitis B Patient from Stigma and Discrimination and outcome after disclosing my status.

By 2030 we aim to:

Eliminate Stigma and Discrimination associated with Hepatitis.

Eliminate Hepatitis
Introduction

The universal declaration of human rights affirms the inherent dignity, equality, and inalienable rights of all members of the human family. The rights of all members of indigenous populations are included in this declaration. However, “We have....tools and initiatives that we can build on to address stigma and discrimination.”

“I used to think that the worst thing in life was to end up alone. It’s not. The worst thing in Life is end up with people who make you feel alone.” – Robin Williams (1951-2014)
Introduction

• Chronic viral hepatitis is a major public health issue worldwide
• Resource-limited countries are the most affected
• Considerable set of barriers to contain the epidemic
  – Shortage of healthcare workers
  – Poor medical infrastructures
  – Insufficient screening and poor access to care/treatment
• Raising awareness about viral hepatitis is crucial to:
  – Effectively reduce the number of new infections
  – Ensure treatment reaches those who need it
  – Fight social stigma
• Stigma and discrimination towards people with Hepatitis has been associated with negative health outcomes for affected population in Africa
• Some patients choose to avoid disclosing their status to prevent discrimination from family, friends, spouse and healthcare workers
The MSN Encarta Dictionary defines *stigma* as “a sign of social unacceptability: the shame or disgrace attached to something regarded as socially unacceptable.”

According to the US Department of Health and Human Services, “*stigma is about disrespect.*”

Deciding whether or not to tell your boss you have Hepatitis B/C is a multifaceted issue that requires education, planning and support.

Sharing your Hepatitis status with employers or coworkers or mates or parents can be riddled with complexity.

There are many factors to consider before disclosing that you have Hepatitis.
“It’s My Secret”: Fear of Disclosure

Stigma and discrimination towards people with hepatitis has been associated with negative health outcomes for affected populations in Ghana and Africa.

Disclosing one’s Hepatitis status has been examined closely, particularly looking at the positive and negative aspects of disclosure. On one hand, disclosing one’s status can, in some settings, negatively affect access to housing, education, and employment (Hadjipateras, 2004).

However, disclosing one’s status can also offer an opportunity to find psychological and social support through those in similar situations, decrease stress, and facilitate appropriate and necessary treatment (Edwards, 2006; Link & Phelan, 2006; Paterson et al., 2007).
Hepatitis Related Stigma and Effects

Both stigma and discrimination has huge effect on the management of the disease

- Delay in diagnosis
- Delay in entry into treatment
- Adoption of a healthy lifestyle
- Causes fear in disclosure of illness
- Restriction in participation involving activities of life and depression
- Fuel the spread of the disease

Stigma often occurs when an attribute creates a gap between

- Who we think we are (our actual social identity)
- How we are seen by others (our virtual identity)

This gap creates a spoiled identity that often cuts the stigmatized person off from the society and from himself so that he stands as a discredited person against an unaccepting world
Hepatitis Related Stigma and Effects

This fear, coupled with many other reasons, means that lots of people falsely believe:

- Hepatitis is always associated with death
- Hepatitis is associated with behaviours that some people disapprove of (like sex)
- Hepatitis is only transmitted through sex which is a taboo subject in some cultures
- Hepatitis is transmitted through kissing, coughing, hanging and breastfeeding
- Hepatitis infection is the result of personal irresponsibility or moral fault and that deserves to be punished
- Inaccurate information about how Hepatitis is transmitted, creating irrational behaviour and misperceptions of personal risk
How Stigma Affects People Living with Hepatitis

Hepatitis-related stigma and discrimination exist worldwide, although they manifest themselves differently across countries, communities, religious groups and individuals.

The Possible Consequences of Hepatitis-Related Stigma to be:

- Loss of Income
- Loss of Marriage and Childbearing options
- Poor Care within the Health Sector
- Withdrawal of caregiving in the home
- Loss of Hope and Feeling of Worthlessness
- Loss of Reputation
- Mental disorders like depression
Breaking a Hepatitis Related Stigma

The stigma of living with Hepatitis is more harmful than the virus itself.

There are two ways of breaking Hepatitis related stigma:

**Education**

Any social stigma finds its roots in fear of the unknown. Many Ghanaians have misconceptions about the way hepatitis is transmitted.

Educating yourself and others will break down the stigma associated with Hepatitis.

**Self-Respect**

If you have Hepatitis the first step in breaking the stigma is to start with your own attitude toward your illness.

Do you label yourself as a sick person? Do you expect to be shunned from co-workers, friends and family? Do you feel like you deserve to have Hepatitis?
Disclosure Steps

- Be selective. Choosing whom to tell or not tell is your personal decision.
- Consider the five "W's" when thinking about disclosure: who, what, when, where and why.
- Easy does it. In most situations, you can take your time to consider who to tell and how to tell them.
- Consider whether there is a real purpose for you to tell this person.
- Having feelings of uncertainty about disclosure is a very common reaction.
- You have a virus. You don't have anything to apologize for simply because you are Hepatitis positive.
- Keep it simple. You don't have to tell the story of your life.
- Avoid isolating yourself
- There's no perfect roadmap for how to disclose. Trust your instinct, not your fears.
- Even if the response you receive in a specific situation, doesn't go the way you'd hoped, you're going to survive it and your life will go on.
- Millions of others have dealt with this experience and have found their way through it. You will get through it too.
Barriers of Disclosing Hepatitis Status

- Negative experiences with previous disclosures
- Fear of discrimination
- Stigma and rejection
- Lack of a strong social network
- Feelings of shame and guilt regarding one’s Hepatitis status
- Self-acceptance of Hepatitis-positive identity

- Struggle with Hepatitis+ identity
  - Cultural factors within one’s community
  - Lack of Hepatitis education and inability to cope with the outcome of the disclosure
  - Concern about harming or burdening others
  - Trust in the person receiving the disclosure

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The Impacts and Outcomes of Hepatitis Disclosure

Negative outcomes include

- Rejection,
- Abuse,
- Violence
- Stigma and discrimination
- Low self-esteem

Positive outcomes include

- More high quality social support,
- Stronger family cohesion and relationships,
- Reductions in anxiety and depression,
  - Improvements in physical health.
  - To relieve the stress of keeping their HBV/HCV status a secret
- To share knowledge
- To control disclosure (i.e. to disclose before someone else exposes them)
- Save your love ones
Factors That Can Affect Individual’s Decision to Disclose or Not At Workplace

- The sector they work in (public-sector employers are often perceived to be more supportive)
- Whether the nature of the work could give rise to unfounded fears of Hepatitis transmission (this particularly affects people working in health care, teaching, personal-care work or food preparation)
- The general atmosphere at work (very tough, competitive or political environments may feel less supportive or safe)
- How trustworthy managers, human-resources staff or colleagues are perceived to be
- A strong, positive relationship with a particular manager or colleague
- How secure the employment is
- What their other options are if a disclosure is not well received or is badly handled
ROLE  As a PATIENT

• Make sure you know the truth.
• Get accurate information about viral hepatitis.

  Some people mistakenly believe Hepatitis (B or C) is an automatic death sentence.
• Don’t make things worse by imagining a future with pain, disability or loss.
• Maintain perspective of the big picture
• Watch your words
• Learn what you can control and what you cannot.

Improve your odds by visualizing your future the way you want it. Visualizing health, not illness, is a powerful tool for self-transformation.

• Learn from the virus. Ask yourself what Hepatitis (B or C) can teach you about living.
• Get support. Being with others who are dealing with the same issues can bring encouragement and hope.

Join the Hepatitis Foundation of Ghana.
Help others.
Active participation in educating your community on viral hepatitis.

This will help in breaking the Hepatitis stigma and helping those diagnosed with the disease.
Conclusion

Before disclosing you have Hepatitis at work or Home, carefully consider all of your options and the potential implications.

Be aware of the stigma associated with Hepatitis and people’s most common fears so that you can fully educate your employer or coworkers.

Decide if it is in your best interest to disclose this personal, medical manner by being aware of what legal rights you may or may not be entitled to.

With the right preparation, knowledge and support, those with Hepatitis can make the best possible decision about disclosing their illness at work.
Access to treatment is Patient right not privilege

Thank you for your attention

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