Recognising identity among those with chronic illnesses

A key to economic recovery?

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Chronic Illness Forecast

Above 12.5%
The Economics of Health

• Health Care Expenditure
  1990  3.1 billion
  2010  14.849 billion
  479% Increase

• Drug costs higher than in other European countries – up to 50%

• Cost controls – up to 70% spent on staff costs
### % CHRONIC ILLNESS CONDITIONS REPORTED IN IRELAND AND EU-27, 2008 (CSO)

<table>
<thead>
<tr>
<th>Age Group</th>
<th>% Male</th>
<th>% Female</th>
<th>% Male</th>
<th>% Female</th>
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<tr>
<td>16-24</td>
<td>12.4</td>
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<td>13.7</td>
<td>13.5</td>
<td>86.3</td>
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<td>30.8</td>
<td>71.0</td>
<td>69.2</td>
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<tr>
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<td>52.3</td>
<td>55.1</td>
<td>47.7</td>
<td>44.9</td>
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<tr>
<td>Total</td>
<td>23.3</td>
<td>25.0</td>
<td>76.7</td>
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<tr>
<td>EU-27</td>
<td>28.7</td>
<td>32.8</td>
<td>71.3</td>
<td>67.2</td>
</tr>
</tbody>
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The Cost of Chronic Pain 4.7 billion per annum
It is ‘the individual mind, interaction with others, the degree of reflexivity and the structures of society’ (Kelleher 2004:87) which construct the identity of an individual.

Chronic Illness affects identity in relation to both the individual’s private life and public roles and responsibilities, including relationship difficulties and experience of stigmatisation.

A stereotype developed against me by others impinges on my self, and if it gets into it, it is an obstacle to my living freely or effectively in a convinced way. But an identity that I embrace is an aid to living in such ways. The difference between an identity which is mine, and an identity as what someone else simply assumes me to be, is in one sense all the difference in the world (Harris 1995:8).
Illness Behaviour

• The ways in which ‘given symptoms may be perceived, evaluated, and acted (or not acted) on’ (Mechanic 1962)

• ‘Secondary personalities often result from the splitting of what ought to be a single complete self into two parts, of which one lurks in the background whilst the other appears on the surface as the only self the man or woman has’ – William James (Martin 2003:63)
Sociology of Chronic Illness

- Has brought theory to the ‘steps people take to manage, mitigate, or adapt to it, and the meanings attached to these actions’, where interactionist models of illness provide ‘a means of understanding better the social basis of the meanings of symptoms, and the negotiated reality actors fashion in response to them’ (Bury 1991:452)
Shifting Perspectives Model of Chronic Illness

Perception of the illness, not the illness itself, is more important

Illness in the foreground  Wellness in the foreground

Social Structures & Identity Disruption

• Social economic stratification and social institutions influence identity. Social structures such as family, relationships, education, employment, and culture both enhance and impair identity.

• When a chronic illness strikes an individual identity disruption flares, creating social and economic consequences that impact and impede on identity and life quality. The label of the illness creates an identity, a role which the individual inevitably succumbs to.
Identity dilemmas arise from the suddenness of chronic illness, its intensity and its timing during the life course (Strauss 1997:37). Strauss (1997:37) noted that ‘identities define, locate, characterise, categorise and differentiate self from others. Identities develop in stable roles and emerging situations’.
Lupus Statistics

• Rate of lupus has tripled in America over the past four decades
• Over 1.5 million Americans have lupus, a figure that presides over ‘cerebral palsy, multiple sclerosis, sickle-cell anaemia, and cystic fibrosis combined’ (American SLE Lupus Foundation).
• ‘Up to ten years ago there were few cases of SLE diagnosed here in Ireland. Today, it is increasingly diagnosed and is becoming one of the more general conditions facing doctors’ The Irish Lupus Support Group (2009)
Statistics on Symptoms

• About 50 percent of systemic lupus erythematosus patients will have neuropsychiatric disorders such as seizures, memory loss, headaches, or depression

• Women with systemic lupus erythematosus have an increased risk of developing heart disease

• Between 40 and 60 percent have some form of photosensitivity

• About 10 percent of people with lupus will have symptoms of one or more other connective tissue diseases.
Everyday Symptoms

• Weight loss, chest pain, fatigue, fever, nausea, anaemia, kidney disorders, chronic fatigue, joint/muscle pain, hair loss, flu-like symptoms, migraine, body/facial rashes, oral/nasal ulcers, depression, miscarriage, reaction to sunlight/UV light, kidney problems, heart or lung damage, brain involvement

varied symptoms + unexpected flares = identity crisis = loss of self = stigma & social isolation
Moriarty et al. (2003)

• **Systemic Lupus Erythematosus in Portugal: Diagnosis and disease awareness from 1970s to 2001**

• Lack of awareness of SLE amongst patients and in the general population has been implicated in many of the stresses associated with the condition and in affecting patient quality of life.

• In the only other published investigation of trends in awareness, pre-diagnosis knowledge of the disease in a patient cohort in the Republic of Ireland was found to remain relatively constant over the 1970-1997 study period, at a level comparable with that observed in the Portuguese population prior to the dramatic increase seen in 1994-1995. (2003:998)
Women with systemic lupus erythematosus (SLE or lupus) often experience a protracted diagnostic period in which their symptoms are treated as medically unexplained. Although they know they are ill, their symptoms have not been validated as indicative of disease by a health care professional. Consequently, the diagnostic period and what Turner (1967/1997) has labelled ‘betwixt and between’
Lupus support and awareness in the Republic of Ireland

• Over the past four decades, the marked improvement in survival in SLE has not been accompanied by an improvement in quality of life, and it has been suggested that the modern challenge for rheumatologists is to improve the quality of life rather than duration of life for SLE patients. SLE threatens not only the physical well-being: quality of life is adversely affected by deficits in social interaction and others’ lack of understanding of the disease.

• Less than one in five respondents (19 percent) in our surveyed population had heard of lupus prior to their own diagnosis...Respondents also indicated...that the low level of public awareness of lupus creates difficulties for them in all aspects of their lives.
Family and friends can be seen as a factor in making it possible to live an independent and active life as well as an important factor for enhancing security (1999:415)

Suffering from a chronic disease impacts the way different life roles can be expressed. There is also a risk of losing some of them such as the work role, which may make the family role as well as being a member of the family even more important (1999:415)

The disease as well as income, relationships and social services all influence the experience of quality of life (1999:417)
Identity Experience and Family

• Someone who has shadowed my every move for the past couple years, the obvious suspect, if you will. And yet, it happened in such a mind-boggling whirlwind of prescription drug bottles and countless specialist visits and blood tests, that even I was unaware it was happening. That’s right - Lupus has stolen my identity. And it took a good hard look at my driver’s licence picture, one that was taken only 2 years ago on my 21st birthday, to realize it.

• I could barely recognize the person staring back at me. She had long blonde hair, a big smile, no butterfly rash and looked healthy, full of ambition and ready for the future and what it had to offer. Now granted, even during the time this picture was taken, I was in the process of being diagnosed, but nonetheless, I looked healthy, I looked “normal.”

• I looked like Kimberly Lehanka... The goofy, silly and carefree girl I had been my entire life. But since then, and upon my diagnosis that May, I cannot help but feel that my body has undergone a major transformation, whether it has been for the good or bad has yet to be seen, but if I were to be pulled over or ID-ed at a bar, I am pretty sure I would be accused of having a fake ID, as the girl in the licence does not even slightly resemble the person I am today.
As many of you know, or perhaps you don’t... Lupus is considered an “invisible Illness” . However; its effects and the side effects of the medications are not always so invisible. It takes a physical toll on your body, and even the mental and emotional toll contribute to the physical changes that your body undergoes. From the steroids that usually bloat people (although in my case, I tend to not blow up on it, I still have the muscle wasting in my legs, the dry skin and some lovely other side effects that come with the prednisone), to the side effects/symptoms of the disease itself, that can cause such a broad range of delightful symptoms, my most recent being losing all of my hair in a lupus flare that caused alopecia.

Now, although my hair has begun to grow back, the person that stares back at me when I am looking in the mirror does not reflect the person I am... Or perhaps it does, but I have yet to come to terms and accept this ‘new’ me I have been forced to become.

But luckily, I am blessed and surrounded with loved ones, both friends and family, that have supported me through thick and thin, and because of the strength and guidance they offer me, I am slowly starting to “recognize” the new reflection in the mirror... the “new” me.
Lay people were trained to listen actively and to provide compassionate, unconditional love to others with the same chronic disease.

The peer telephone supporters showed pronounced improvement in confidence, self-awareness, self-esteem, depression and role functioning.
CIISN Seminar Series
Health in Crisis