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Unique aspects of women’s emotional responses to disability

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Abstract

Purpose. To improve rehabilitation clinicians’ awareness of gender differences in emotional responses to disability as a means of enhancing accuracy and sensitivity in diagnosis and treatment of persons in their care.

Method. A prospective survey study using a new grief measure, the Loss Inventory (LI), with a diverse convenience sample of persons undergoing inpatient rehabilitation in the USA. Focused review of the bereavement, depression, and disability literatures related to observed gender differences.

Results. Study participants reported grief symptoms in varying intensities. Consistent with all literature reviewed, significant gender differences were found in kind and intensity of grief and depression symptoms reported. Ethnicity also significantly affected responses to disability by LI study participant responses.

Conclusions. While persons with disabilities as a whole may not necessarily develop depression, gender is a risk factor for onset of mood problems after illness or injury-related losses. As compared with study sample disabled men, disabled women reported more intense and different symptoms of grief and depression. Women with disabilities in the LI sample were twice as likely as disabled men to be depressed. Rehabilitation clinicians may wish to incorporate consideration of these differences in their mental health assessments, diagnoses, and treatment plans.

Keywords: Disability, gender, grief, depression

Introduction

Despite the findings of the last two decades of bereavement, depression, and adjustment to disability research, gaps remain in our clinical knowledge related to observed gender differences in emotional responses to disability. For example, recent studies show that men and women experience and cope with loss in significantly different ways [1–4]. This paper provides a review of changes and new information of the last two decades of study in these separate but related fields to improve rehabilitation clinicians’ awareness of observed gender and ethnic differences as well as to highlight the unique emotional needs of women with disabilities. The author additionally reports findings of the ongoing study of a new grief scale, the Loss Inventory® [5] with this review. A plan is offered for incorporating knowledge of response and coping findings from the psychiatric, grief, and rehabilitation literature into psychological assessment and treatment of women who have disabilities.

Bereavement research

The past two decades of grief research have resulted in several significant changes in our understanding of bereavement [6–18]. First, despite overlap [19–21], the symptoms of grief and depression have been distinguished from each other [10,20–26]. Early study of grief in the service of investigating depression led Freud, and subsequently others, to intertwine the two states in their discussions [27–30]. Unfortunately this binding stuck and found its way into the adjustment to disability literature [29–31]. Second, until recently [32] little empirical support has been found for the stage theories of bereavement [6,20,33–36]. In addition, while grief theory is an implicit in discussions of the process of adjusting to disablement, recent controlled efforts to apply these
models to recovery from injury have not resulted in a
good fit [37,38]. As a result, other models such as
trauma, Stress-Coping social support, and ambig-
uous loss, are being explored for explaining re-
sponses to injury or illness-related losses [7,39 – 46].
Third, there is little evidence that psychotherapy is
necessary for ‘resolution’ of grieving [13,14,20,46].
However, qualitative researchers have practiced
alternative methods, ‘narrative reconstructions,’ for
facilitating adjustment to disability following disable-
ment [47 – 50] Fourth, no specific ‘normal’ time
period or ‘show’ of grief is yet fully empirically
substantiated [6,14,20,24,51]. Fifth, clinicians observe that focus
on positive emotions results in better adjustment
following bereavement [7]. Finally, grief inventories
are being used to reliably measure type and intensity
of grief symptoms allowing meaningful exploration
of this process [5,18,22,23,25,26,52,53].

Gender differences and bereavement
Bereavement researchers have learned that women
experience different and significantly higher levels of
grief symptoms than men do [1 – 4,20]. In addition,
in comparison to men, women report significantly
more symptoms of depression and anxiety during
bereavement [2 – 4]. In fact widows are significantly
more likely than widowers to develop depression
after bereavement if older than 55 years, report sleep
disturbance, and have a history of depression
[2,4,15]. However, widowers, as opposed to widows,
are significantly more likely to have suicidal ideation
and to cope using alcohol excessively [1]. These
latter findings are consistent with the general
observation of gender differences in coping styles
during bereavement with men more likely to be
withdrawn and women more likely to be involved in
multiple community-based activities [1 – 3]. Re-
searchers also observe that intensity of grief symp-
toms reported six months after death of a significant
other is associated significantly more often for
women than for men with risk for a major health
event such as cancer or a heart attack at 25 months
follow-up [4]. Finally, investigators have found that
bereaved African American women report having
significantly less social support during bereavement
than African American men [4].

Gender differences and depression
The observation of significant gender differences in
the emotional and coping responses to bereavement
are paralleled in the depression literature. For
example, depression is twice as common for women
than men, across all age groups [54 – 56]. Women
are also significantly more likely than men to have
atypical symptoms, sleep and appetite disturbances,
a co-morbid anxiety disorder, to attempt suicide, and
to be diagnosed with Season Affective Disorder
(SAD) [55,56]. However, men are significantly more
likely to successfully commit suicide [55].

Challenges and imperatives for rehabilitation providers
The findings of both the bereavement and depression
literatures have significant relevance for persons
recovering from disabling illness or injury though
integrative discussions are infrequent. Persons with
disabilities certainly experience significant losses:
Functional skills and abilities, role in family, work
and related social network, appearance, cognitive
abilities, independence, hair, extremities, etc. It is
therefore understandable that theories of adjustment
to disability draw heavily on bereavement theory.
However, the current paper addresses some difficul-
ties with this application. For example, disability
researchers need to consider differences as well as
similarities in the experiences of disabled and
bereaved persons so that they, like grief theorists,
will not apply models with little empirical support
[5,6,12,14]. In addition, disability researchers need
to incorporate findings of the last 20 years of grief
research in their models of cognitive and emotional
responses to disablement. Barriers to incorporation
include the restrictive psychiatric diagnostic termi-

ology [5], symptom overlap of grief and depression
[9,19,21], the current in-flux status of bereavement
theory [6], the diversity of the disabled population
[5], and lack of appropriate measures of emotional
responses to illness- or injury-related losses
[5,52,53]. Furthermore, grief over loss of a person
is often seen as totally different from emotional
responses to other types of losses. Fortunately, loss
and disability researchers have increasingly called for
consideration of the potential emotional and physical
impact of a wider variety of disabling and life
experiences [5,6,20,41,39 – 45].

Several factors argue importantly for extending use
of the bereavement terminology and descriptors to
the experience of disability. First, there is general
agreement that loss and grief are a part of the
disability experience [5,57,58]. Second, disability
researchers need to develop a theory of adjustment
to disability that relies less on bereavement models that
are largely empirically unsupported [6]. Third, the
terms ‘grief’ and ‘depression’ are often used inter-
changeably in the adjustment to disability literature,
a practice which may not be justified and promotes a
practice of treating patients grieving about illness and
injury-related losses as if they are depressed
[5,12,29]. However, assessment and diagnosis of
mood and coping during disablement present quite a challenge for rehabilitation clinicians because of symptom overlap between physical manifestations of illness, normal grief, dysphoria, and depression [5,19,21]. The current paper proposes use of a fundamental distinction to help providers improve diagnostic accuracy of emotional status after disablement. Grief needs to be seen as an essentially normal emotional process. In contrast depression is a psychopathological process. However, we know that grief can have a negative impact on the physical, psychological, and behavioral health of people who are well [1,15]. It is thus important to remember that grief has the potential to worsen the health of disabled persons who are already physically and cognitively compromised because of illness or injury. Fortunately, while there is some overlap of emotional and physical symptoms, depression and grief have distinguishable cognitive symptoms [5]. Figure 1 presents some differences between the cognitive and emotional manifestations of uncomplicated grief and mood and anxiety disorders.

Rehabilitation clinicians need to consider all possible emotional reactions to disability. Clinicians often assume that a disabled person’s show of feelings is symptomatic of pathology, i.e., tears = diagnosable depression or adjustment disorders. In addition, tests available to psychologists in rehabilitation and medical settings for assessment of emotional and cognitive responses to disability are primarily designed to identify pathological rather than normal coping processes. Furthermore, most commonly used mood assessments risk overestimates of pathology because test items related to physical symptoms could simply reflect patients’ actual illness/injury symptoms rather than vegetative signs of a mood disorder. In the past several years some authors have challenged use of these tests as they do not help identify and understand symptoms, thoughts, and feelings unique to grief [5,12,14,21].

The Loss Inventory

Until recently, other than qualitative assessment methodology, there was no specific measurement tool for assessing normal grief feelings related to injury or illness-related functional and cognitive losses. Niemeier et al. [5] developed the Loss Inventory (LI) to address this need. The 30 LI items were derived using existing grief inventories designed to measure intensity of grief following loss of a person [18,22,23,25,26]. However, the wording of the LI contrasts with these original bereavement measures by reflecting only functional losses due to disability rather than to loss of a significant person through death. The content of the LI items reflects the full range of grief symptoms identified by prior bereavement researchers. The LI was developed to provide measurement of normal emotional responses to functional losses following disablement. Prior work with the LI has established that the measure’s reliability is respectable (Cronbach’s Alpha = 0.93, Test-Retest = 0.91). The Zung Self-Rating Depression Scale (ZSDS) [59,60] was given to investigate the relationship between grief and depression in this setting and as a potential measure of divergent validity. The Zung is a 20-item Likert scale which requires patients to rate themselves on the frequency with which they experience such symptoms of depression as crying, hopelessness, and sleep disturbance. The ZSDS has been validated in many medical populations [59,60].

<table>
<thead>
<tr>
<th>Uncomplicated bereavement</th>
<th>Depression and anxiety disorders</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequent thoughts about the loss (can be positive or negative)</td>
<td>Persistent negative thoughts</td>
</tr>
<tr>
<td>Sadness, crying, tied to thoughts about what was lost</td>
<td>Excessive crying or inability to cry</td>
</tr>
<tr>
<td>Anxiety tied to separation from the person or lost object</td>
<td>Anxiety tied to irrational fears/thoughts</td>
</tr>
<tr>
<td>Appropriate guilt about what could have been done to prevent the loss</td>
<td>Morbid guilt and self-blame</td>
</tr>
<tr>
<td>Yearning for the lost object</td>
<td>Paranoid thinking</td>
</tr>
<tr>
<td>Shock and disbelief</td>
<td>Delusions</td>
</tr>
<tr>
<td>Sense of presence of the lost object/person</td>
<td>Auditory and visual hallucinations</td>
</tr>
<tr>
<td>Fleeting wishes to die, join the person</td>
<td>Suicidal thoughts, plans, gestures</td>
</tr>
<tr>
<td>Normal motor responses if no neurological compromise is present</td>
<td>Motor slowing in the absence of neurological compromise</td>
</tr>
</tbody>
</table>

Figure 1. Symptom differences between grief and psychiatric disorders (Niemeier et al. 2004) [5].
The LI begins by asking the person being assessed what losses they believe they have sustained as a result of their illness or injury. These initial identified losses then serve as the basis for the rest of the patient’s responses to the 30 items of the measure. The person taking the LI is asked to rate how often they experience (‘Never,’ ‘Rarely,’ ‘Sometimes,’ ‘Often,’ ‘Always’) such symptoms as ‘I feel like crying when I think about what I have lost,’ or ‘Thoughts of what I lost come to me when I least expect them,’ or ‘I long to have what I lost again.’

Based on the literature reviewed the following hypotheses were developed for the current study with the LI:

1. Grief symptoms will be reported in varying intensities by the study sample;
2. A subset of persons who have high LI scores, will have low ZSDS scores;
3. Women will report significantly greater intensities of grief and depression symptoms than men in the study sample as measured by means on the LI.

Method
Participants
The LI sample currently consists of 198 patients in both general and brain injury rehabilitation units of a level one trauma hospital in an urban setting. There are 89 (45%) females and 109 males (55%). With regard to ethnicity, there are 94 African American (47%) and 104 Caucasian patients (53%). The LI study sample can be further stratified according to gender and ethnicity. The sample includes 52 African American men (26%), 42 African American women (21%), 57 Caucasian men (29%), and 47 Caucasian women (24%). Diagnoses include 51 (25%) persons with stroke or aneurismal bleeds, 64 with spinal cord injury (33%), 41 with traumatic brain injury (21%), and finally a category of 42 persons with ‘other’ diagnoses (21%) including neuromuscular disorders, brain tumors, amputations, and general debilitation. The average age of the sample is 45 years, 179 days (SD = 15.56, range 19 – 84). Mean time from injury or illness onset to date of testing is 40 days (SD = 38.51, range 6 – 290). Compared to the occurrence rate in the non-medical population, the sample’s percentage of persons with a history or diagnosis of depression is high at 31%. Further stratification into gender/ethnicity/diagnostic categories for purposes of analyzing within group differences would not be currently meaningful given power limitations. However, the possible impact of these variables and interactions are planned for future LI research.

Procedure
All participants in the LI study were consented with a Virginia Commonwealth University Institutional Review Board approved form. The study was explained clearly and the patient was given at least 24 hours to review the form and decide if they are willing to participate. Following explanation, eight true-false questions established whether the patient had understood the explanation. When the patient was deemed by the neuropsychologist to have diminished capacity to understand because of brain injury, the person was either not recruited or a legally authorized representative was asked to sign for the patient after explanation.

Following the consent process the LI and ZSDS were administered to the patient. One day after the first administration of the first LI, a second LI was given. The patient was provided with feedback about their performance. In the case of a high score indicating severe depression, the patient’s attending and the patient were told that assessment and treatment of possible mood problems was indicated.

Analyses
Means and standard deviations for both the Loss Inventory and the Zung were computed for the entire sample. Analyses were performed on the LI and Zung scores using t tests. In addition, t tests were performed with individual items from each measure to determine whether gender or ethnicity significantly influenced responses. Pearson Product correlations were performed to investigate possible effects of age, length of rehabilitation stay, and time between disablement and testing. One-way ANOVA was used to determine whether membership in a particular diagnostic group affected type and intensity of symptoms reported.

Results
Hypothesis [1] was supported. Both men and women who participated in the study reported both grief and depression symptoms in varying intensities.

Support was also found for Hypothesis [2] of the study. While a 0.58 correlation between the LI and the Zung Self-Rating Depression Scale revealed some expected overlap, the distributions differed, suggesting important distinctions. In addition, a subgroup of participants (n = 23) with LI scores in the top 20% had ZSDS scores below the cut-off for mild depression. This subgroup represented 12% of the sample.

Hypothesis [3] was supported. Men, women, Caucasians, and African Americans participating in the LI study reported significantly different kinds.
and intensities of grief symptoms. In addition, types of losses identified by LI study participants also varied with gender and ethnicity. Women tended to report losses related to care giving and social interaction – ability to care for others (p < 0.01). Use of arms and hands (p < 0.01), speech and communication skills (p < 0.05) – significantly more frequently than men. Tables I and II present means and standard deviations of the LI and Zung Self-Rating Depression Scale for gender and ethnicity.

In terms of percentages, women in the LI sample were twice as likely to be depressed (p < 0.05) as men.

Female participants endorsed certain LI items significantly more often than men, including ‘I feel like crying when I think about my loss’ (p < 0.01), ‘Memories of how I was before my loss upset me’ (p < 0.01), ‘I am envious of others without this loss’ (p < 0.05), ‘I have the urge to cry when I think about my loss’ (p < 0.01), ‘I feel the need to talk about my loss’ (p < 0.01), and ‘I feel panic’ (p < 0.05).

African Americans and Caucasians also differed in the type of reactions to losses they endorsed. Caucasian participants were significantly more likely to report envy of others without losses (p < 0.05), not feeling like a whole person since their loss (p < 0.05), feeling anxious (p < 0.05), feeling guilty about having their losses (p < 0.01), and feeling that their situation was unreal (p < 0.05). Prior history of mood disorder also affected participants’ responses to the LI.

Persons with a current or prior diagnosis of depression endorsed the following items significantly more often than persons without depression: ‘I feel like crying when I think about my loss (p < 0.05), ‘I am angry about my loss’ (p < 0.05), ‘I am envious of others who have not had a loss like this’ (p < 0.05), ‘I don’t feel like a whole person’ (p < 0.01), ‘I need to talk about my loss’ (p < 0.05), and ‘I feel panic’ (p < 0.05).

Analyses of the Zung SDS data revealed trends similar to those found with the LI data. As compared to men, women LI study participants were significantly more likely to score in the depressed range of Zung scores and to report feeling depressed (p < 0.05), having crying spells or feeling like it (p < 0.01), sleep disturbance (p < 0.05), and reduced enjoyment of sex (p < 0.01). Within these gender groups, African American participants were significantly more likely than Caucasians to report physical symptoms but significantly less likely to report reduced enjoyment of life or having crying spells (p < 0.05). Age, time since injury, length of rehabilitation stay, and type of injury did not significantly affect these results.

Discussion and conclusions

The LI study findings provide support for the notion that persons experiencing losses due to disability report the same kinds of grief symptoms that are reported by bereaved persons, and in the same range of intensity. The study participants reported classic bereavement symptoms of shock, numbness, disbelief, sleep disturbance, and longing frequently and in varying levels of intensity.

While as a whole, this study population did not necessarily develop depression as a result of their losses, there was a 0.58 correlation between the LI and Zung scores suggesting a fairly strong association between the two states. The significant effect of history of depression found in our analysis, and the high percentage of persons diagnosed with depression in the study sample, may partially explain this relationship. However, the origins of the diagnoses for this sample were varied and, at times, unclear. In addition, these patients were tested early in their disablement experience. It may be that later adjustment challenges and recovery realities would have greater impact and lead to mood problems.

Gender significantly affected the kind and intensity of grief symptoms our disabled participants reported. These findings are consistent with the psychiatric literature showing that women are twice as likely as men to be depressed [54–56]. Compared to men with disabilities, women of all races in our sample
were more likely to develop depression, to talk about their feelings and circumstances, feel like crying, and report sleep disturbance. Gender also significantly influenced the kind of losses identified by our study sample. Male participants were more significantly more likely to report grief about losses of motor abilities, work and income, and independence. Women were more likely to report intense grief related to communication deficits, impairment of their upper extremities, and reduced ability to care for significant others.

While not as prominent an effect, ethnicity also significantly influenced the symptoms of depression reported. Consistent with the literature [61], African Americans were significantly more likely than White to report physical rather than emotional symptoms of depression.

The complexity of the LI findings in combination with the information from the reviewed literatures about gender differences in grief or depression symptom presentation, coping responses, and rate of occurrence emotional disorders underscores the diversity of the rehabilitation patient population. Several approaches to the assessment and treatment of persons with disabilities, particularly for women and minority persons undergoing rehabilitation, are recommended in order to meet the challenge this heterogeneity. While some dysphoria can be expected when one experiences losses due to illness or injury, clinicians may need to look beyond the general population base rate. For example, the total sample of patients in the current LI study have an average Zung SDS score right at the cutoff between normal and mild depression. Thus one could conclude that patients with disabilities may grieve but are not much more likely than the general population to develop depression in response to their losses. Indeed, there was a subset of our participants with high scores on the LI and low scores on the ZSDS. However, 43% of the LI sample of women had a current diagnosis or history of mood disorders. It is thus important for clinicians to consider within group differences when assessing emotional status and coping.

The results of the LI study leads to a recommendation for use of more than one method of assessment of mood and coping. Qualitative methods of assessment, such as the interview so successfully used by Bury [47–49] and Williams [50] to explore the process of incorporating the disablement into one’s identify and ongoing life story, yield unique information about each patient’s responses to disabilities. Assessment of normal emotional responses to loss after disability using the narrative method or instruments like the LI may prevent overpathologizing reactions and inappropriate prescriptions for psychotropic medications.

Further research into gender and ethnic differences during the adjustment to disability process will increase rehabilitation providers’ awareness. As a result, clinicians may be better able to avoid logical errors like confirmatory and familiarity bias [62] during the potentially pivotal choice points of diagnosis and treatment recommendations. Confirmatory bias would be the unintentional tendency to come to conclusions based on stereotypic views of certain gender or ethnic groups. Familiarity bias would be drawing clinical conclusions based on a limited experience with specific patient populations. Treatment and recommendations that are delivered with greater sensitivity and more accuracy will be less likely to be experienced by women or minority patients as either irrelevant or harmful. Considerations that incorporate what we have learned about how women uniquely experience and respond to disability will also help lessen medical and mental health disparities.

Specific preventive intervention strategies are suggested by the LI study results. Assessment strategies that employ multiple measures will be more likely to accurately characterize women’s normal adjustment processes without overlooking depression in this high risk group. Furthermore, women experiencing grief about losing functional and cognitive abilities are more likely than men to feel it is important to talk about their losses. Women are particularly disturbed by losses related to valued roles of care giving and communication. Even though psychological assessments may not turn up pathology suggesting a need for supportive psychotherapy or psychotropic medication, women undergoing rehabilitation for disabilities may benefit from a support group or just individual time with a provider to talk over their feelings.

Certain limitations of the LI study make ongoing research important. For example, small numbers of participants result in power being insufficient at this point in time to examine the impact of other variables such as diagnosis or spirituality that may have influenced results. In addition, the origin of preexisting diagnoses of depression in the study participants was not always clear. Persons with more severe disabilities, especially brain injury, were not able to participate limiting the generalizability of these findings.

Future plans include a factor analytic study of the LI to look at validity and the most prominent aspects of the grief process following disability. In addition, a repeated measures study is also planned with a goal of clarifying the grief process following disability. Perhaps an identifiable grieving ‘process’ can be characterized, not unlike the recent evidence-based model presented by bereavement researchers [32],
through assessment of intensity of grief starting with onset of the disability and continuing over several time periods. Better understanding of the course of normal emotional and cognitive responses to disability may help us more easily identify and treat pathological reactions.

References