Reworking identity/identities in the face of illness and disability

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Sontag (1978)

• ‘Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick’

• ‘Yet it is hardly possible to take up one’s residence in the kingdom of the ill unprejudiced by the lurid metaphors with which it has been landscaped.’
Disruption btw past, present and imagined future

• Disruption to ‘expectations and plans that individuals hold for the future’, requiring a reworking of biography and self-concept (Bury, 1982 - chronic illness)

• Life is not “As One Ought, should and Wants to Be’ (Yngvesson, 2000 - infertility)
Acceptance of illness identity

- Rejection and engulfment of illness identity = greater maladaptive psychological and physical functioning
- Acceptance = greater capacity to adapt psychological and better physical functioning
- Individual, cultural & religious variability
- Illness used to make unrelated claims
Potential responses to disruptions

- Beliefs and memories that help to restore/maintain some sense of continuity
- A ‘turning point’ (Le Shan, 1996)
- Diagnosis, treatment & prior experience mean life dominated by loss
Chronic Sorrow: Roos 2002

• Painful gap between who one has been, the present, who one dreamt of becoming and still long to be
• Pervasive, periodic, and resurgent sadness related to the ongoing losses associated with illness and disability
Constructions of Loss

• Stage-based: denial, anger, bargaining, depression, acceptance (Kubler Ross, 1970)
• Oscillations and cultural variations
• Blame: self-blame vs projection of feared and hated onto another, or another situation (Klein, 1975)
Attachment, Loss & Separation

• Secure, anxious pre-occupied, dismissive avoidant, fearful avoidant (Bowlby, 1988)
• Family scripts - corrective, replicative (Byng-Hall, 1994)
Ambiguous Loss (Boss, 1999)

Loss is unclear, incomplete or partial: person is psychologically absent despite being physically present, or remains a psychological presence despite physical absence.
Disenfranchised Grief (Doka, 2002)

• Loss that cannot be openly mourned, or socially supported as one does not have (or feel one has) a recognized right, role or capacity to grieve

• Circumstances of death expose one to stigma and negative judgement
Living in Limbo - Anticipatory Grief

• Medical advances - Increased longevity
• Genetic pre-disposition – eg. BRCA
• ‘In remission’
• Pending mastectomy, divorce, downsizing and war
Trauma

• Faced with a perceived traumatic event we tend to respond with a generalized discharge of sympathetic nervous system that primes us to fight, flee and if neither possible freeze

• Capacity to think paralyzed in trying to reduce unmanageable quantities of excitation that pour through one’s protective shield
Trauma

• Reflecting on experience can help in confronting and integrating damaged aspects of self into personal narrative
• Where too risky, work towards increasing capacity to engage in everyday activities, alleviate anxiety and re-regulate physiological responses, through relaxation, EMDR, somatic experiencing and mindfulness
• Increase recognition of somatic responses
Rolland’s 3 Factors Affecting Illness

TIME

PHASES

COMPONENTS OF FAMILY FUNCTIONING

ILLNESS TYPE
Factors (Rolland, 1994, 2018)

**Condition:** Onset, course, prognosis/outcome, level of incapacitation, uncertainty, symptom visibility, treatment regime, genetics

**Family functioning:** structure, roles, dynamics & history of support, fit between family and healthcare belief system

**Time phases:** Illness & family life course – in and outward pull
Additional factors

- Prior loss and trauma
- Interactions with friends, extended family, colleagues and school
- Access to care, finances and other material resources
- Cultural constructs: health, illness & care
- Engagement with & resonances for HCP
Challenges to parental identities

• Self care vs caring for others
• Guilt and blame re child and parental illness
• Reworking intergenerational and gendered roles and boundaries
• Prior trauma and family scripts
Parenting and the past

• Post memories: relationship of second generation to powerful, often traumatic, experiences that preceded their births that were transmitted so deeply they seem to constitute their own memories (Hirsch, 1993)

• Memories and stories of resilience
Couple relationships

• Shifts in power and dependency (e.g., gendered and cultural patterns)

• Holding on ‘we’ in a context of difference

• Hold on to ‘I’/difference when one person’s experience is subjugated

• Implications for sexual intimacy
Threat: couple relationships

• Threat of no longer being the person one wants to be plays out relationally, impacting on couple (and parent-child) relationships, all of whom may been through both experiences (Weingarten, 2013)
• Asymmetric acknowledgment of self-loss and other-loss adds to the misery couples/families face: tends to be exacerbated by physical pain
• Attachment
Challenges same-sex couples face

- Many similar to heterosexual couples
- Homophobia, prejudice and lack of understanding of unique challenges
- When this aspect of identity is secret or led to cut off from families
- Shared gendered constructs can mean care more likely to fit with expectations
Identity challenges in later life

• Challenges when unable to care for partners
• Greater chance partners died or too frail to offer care: residential care
• Tensions arising from reliance on adult child
• Neurological conditions seen as breeching social norms more usual
• Less understanding of medical and social care
Culture/religion

- Beliefs about illness, healing and caregiving
- Treatment ‘back home’
- Expressions of emotion
- Engagement with HCP

Migration

- Forced or chosen
- Trauma and uprooting
- Ambiguous loss
- Benefits vs stresses
- Hold onto vs let go of familiar

Family

- Structure and life cycle
- Dynamics, polarisations
- Resiliency, prior loss & support
- Intergenerational and gendered transformations

Socio-cultural/economic context

- Political context & the ‘other’
- Racism and language barriers
- Education and employment
- Risks and protectors
Intersection btw illness and migration

• The death or life threatening illness of a migrant represents the coming together of the most radical thresholds of bodily estrangement and vulnerability:
• Movement across territories and from life to death (Gunuratnam, 2013)
• Movement between assimilation and internal exclusion (Yngvesson, 2010)
• Illness re-evokes trauma of migration
Illness in context of migration

• Medical migrations
  - access to advanced diagnosis, treatment and pain management, respond without taking on cultural traditions and family anxieties
• Absence of taken-for-granted support
• Language and cultural barriers
• Context of healthcare different
• Racism and treatment as the ‘other’
Relational paradox of reunions (Alvarez, 1999)

- Desire to make up for times apart and un-witnessed means we avoid raising issues that might not be resolved in time
- Aimed at maintaining and/or rebuilding authentic connection but tends to have reverse effect (Falicov, 2013)
- Parting in anticipation of final parting
The unhealable rift forced between a human being and a native place, between the self and its true home: its essential sadness can never be surmounted.
کی‌می‌ده آفریقای جنوبی هاچگاه
ILLNESS AND MIGRATION

- Illness factors
- Migration factors
- Socio-cultural/economic context
- Family factors
Clinical work

• Collaborative stance in bearing witness to complex and often enduring nature of trauma, loss, and stress
• Working to address key tasks families face: grieving, restructuring, identity redefinition, and growing through adversity
• Reflecting on legacies of loss, trauma and resilience (genograms or less formally)
Narrative-based ideas

- Questions and comments aimed at bringing forth inherent capacity to be adaptive & resilient
- Hold resilience in trust
- Externalization
- Interview the internalized other
- Witnessing – Imago
- Where polarized and dominated by I/you explore what is shared (visa/versa)
- Where dominated by illness explore other aspects of experience (visa/versa)
Personal resonances

- Own sense of frailty, experiences of illness, disability and other forms of loss
- Transference and countertransference
- Isomorphism
- Engaging with own sense of sadness, fear, disgust and relief
- Remaining alert to own prejudices and the complicated feelings arising from attempts to bridge the gap between our own experience and ‘unfamiliar lives’ (Levinas, 1994)

- Tensions between similarity and difference, sensitivity to the particular and universal

- Listening, taking risks, reaching out across differences and drawing on shared experience of humanity
Beyond the clinical session

• Advocacy where access to care is limited or people do not know how services operate
• Engaging with other community services and key stake holders (including community leaders and traditional healers)
• ‘In loco the family’
  - stigmatized conditions and access to care difficult: HIV mentor mothers
  - GP in relation to refugees & other migrants
Considerations for the profession

• Additional research to establish health needs of migrant and other marginalized groups
• Training to increase understanding of work with illness, disability and death, particularly in relation to cross-cultural work, migration and trauma
Supervision

• Direct clinical work
• Organizational and wider context
• Personal resonances
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