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Module 1:

1.Qualitative Research for Understanding Illness Experience

Illness experience: term to describe the experiences of people with a physical illness
Lived experience: term to describe experience of people who are struggling with mental health issues

Modern Medicine Criticized - Objectify and Dehumanize Patients (Med and Bower)

- In medicine = patient's experience of illness = report of potential existence of disease
- **Major Issues:**
  - Not all cases of illnesses/mental distress can be assigned the same conventional diagnosis
  - Patients bring range of difficulties to consultation with health professionals OTHER THAN actual physical symptoms or mental distress e.g. difficulty managing medications, suffering related to disease/disability, desire for information and autonomy in decision making, family, cultural or social issues that impact on health outcomes
  - Same diagnosis of illness/distress does not mean same experience
    - E.g. leg fracture may not be distressing for an office worker but it may end a career of an athlete
  - Treatments that are the 'same' may have different impacts
    - E.g. impact of surgery - loss of a limb (below the knee amputation) is a very different experience compared to a mastectomy for a woman with breast cancer

Patient more than the 'possessor of the body of disease' (Lawton) - care more important than delivery of medical treatments

- To provide effective care = need to better understand patients actual experience + related needs - RESEARCH ON ILLNESS/LIVED EXPERIENCE = QUALITATIVE
- Illness/lived experience literature explore common themes that occur for people who suffer a particular illness/lived experience of mental distress
- Understanding common issues - help to connect with patients + build trust + help understand how to best manage care
  - E.g. if we understand that young people with diabetes are embarrassed about injecting insulin inn public - we might consider other options for care

Person/Patient Centered Care (PCC)

- **PCC**: ideology of care and a process that privileges the patient's experience and narrative over a clinician-centered or disease centered focus
- Connecting with the person and their family/carers
- **Humanizes care** - focus on person's physical, social and personal history + biography of illness and care
- Emphasize right of person to choose + to be active in their own care
- Support individual's rights, values and beliefs
- **Correlated with:**
  - Better recovery from illness/pain
  - Better emotional health 2 months later, and fewer diagnostic tests and referrals
  - Person-focused approach meant that suicidal men were more likely to return to health services and less likely to attempt suicide

2.Finding research literature and understanding illness/lived experience

Using keywords and subject headings?

- **Keywords**: terms that describe a topic, subject, or concept
  - May be single word or phrase
  - Most databases can be searched with keywords
  - Will find exact terms in article field record (not whole article) e.g. title or abstract
  - Not all articles may be relevant
  - Important to include synonyms or alternate terms in keyword search
    - E.g. cancer screening - can also use mammogram, cancer test
  - **When to use:**
    - when no subject heading available
    - exploring emerging areas = large number of results (some will be irrelevant)

- **Subject Headings**: words or phrases assigned to articles as they are added to the database
  - Describe contents of the article - make them easier to find
  - Medline, Pubmed, Embase
  - Check definition of subject heading using 'scope' button
  - Arranged in hierarchy
  - **When to use:**
    - scoping out a topic
    - have little time to search
    - include as many synonyms as possible (includes international spelling variations) = fewer but more relevant results
- Useful to use combination of keywords and subject headings when conducting comprehensive search (particularly true for systematic reviews)

Search Smarter: creating searching strategies

- **OR**: used to group similar terms
- **AND**: used to connect words together to create search stream
- Use **brackets** to group similar words together

Searching health databases

- **Two types of databases**: Subject Heading and Keywords
- **Three main differences between databases**:
  - Subject headings
  - Search history
  - Limits
    - Can limit your search by age groups, publication type or clinical queries

Finding Qualitative Literature

- Three ways to limit search to qualitative:
  - **Filters**
    - **Clinical queries**: high sensitivity (broadest), high specificity (most targeted), best balance (best balance between sensitivity and specificity)
  - **Subject headings**
  - **Keywords**

3.Some important concepts from illness/lived experience literature - Biographical disruption/loss of self/narrative reconstruction/invisible diseases/stigma

"Lay Experiences of health and illness: past research and future agendas" - Lawton

Modern medicine objectifies + dehumanizes patients (Wallace Bologh)

- Alienating self from body
- Patient = possessor of the body or illness
- Professional dominance of medical system - physicians possess + monopolize medical knowledge = alienates patients from decision-making
- Medical system alone that is responsible for the ways in which patients experience self and body during illness

Wide Range Issues Experienced for Individuals with Disease/Disability - Qualitative Data (in-depth interviews + rich and textured description)

- Stigmatization (real and anticipated)
- Uncertainty and fear
- Strategies employed to avoid and neutralize these phenomena
- Discrimination + isolation within/outside workplace
- Adjusting to + living with different types of medical technologies

Bury's chronic illness as biographical disruption - takes place on many different levels

- Experience of chronic illness can lead to a fundamental rethinking of a person's biography and self-concept
- Chronic illness involves a recognition of the worlds of pain and suffering, possibly even death (normally only seen as distant possibilities or unfortunate)
- Unanticipated diseases = shatter hope + plans for future
  - Disrupt relationships + material and practical affairs
  - **Biographical shif**t from perceived normal trajectory to one fundamentally abnormal and inwardly damaging
  - E.g. arthritis = growing physical dependency on others
- One's ability to mobilize physical and other resources may be crucial to the ways in which illness is experienced

Charmaz's loss of self

- **Loss of sel**f = former self-images crumbling away without a simultaneous development of equally valued new ones
  - Patients with restricted lives, experienced social isolated (discredited by self + others), experience humiliation of being a burden
- Move away from view of suffering = physical discomfort
  - Draws attention to complex and overlapping ways of how illness experience may reinforce and amplify one another
  - E.g. stigma with chronic disease prompt people to experience low self-esteem + withdraw from social activities (quit work, limit social engagements) = absence of opportunities for self-validation
- Restricted life = exacerbates feelings of loss of self

William's narrative reconstruction

- **Conceptual strategies** people employ to create sense of coherence, stability and order in aftermath of biographically disruptive event of illness onset
- Able to explore longer-term effects of chronic disease on self-concepts
- Highlights ways in which **narrative reconstruction** can be used to reconstitute + repair ruptures between body, self and world by linking and interpreting different aspects of biography in order to realign present and past and self and society
  - Participants chose to home in on particular models
  - People's accounts of causation are not simply concerned with beliefs about disease etiology BUT constitute an imaginative attempt to find a legitimate and meaningful place for the chronic illness in their lives

Age, timing and biographies: rethinking 'biographical disruption'

- **Importance of age and stage in life** course of when a person becomes unwell = central theme for concept of biographical disruption
- E.g. stereotype of certain diseases being applicable for certain age groups - RA disease of older people
  - OA being normal and inevitable in later life - older people view symptoms of OA as being normal and integral part of biographies (biologically anticipated event)
- Age and accumulated life experiences of their information appeared to mediate perception + response to illness
  - E.g. working class people elderly "hard earned lives" (familiar with worlds of pain, suffering, death - background exposure to WW2) = although stroke have considerable impact of life (affect how they walk, talk, wash) it was perceived as a "normal crisis" + not really biographically disruptive
    - Already experienced multi-morbidities prior to stroke - already have restricted lives
    - E.g. men who infected with HIV through gay sex view it as biographically disruptive BUT men infect with HIV through hemophilia treatment view it as form of biographical reinforcement
      - Being infected led them to reinforce measures of the sort already taken = no disruption
- Important to look at **person's whole biography** when contracted with particular disease
- **Bury concept scrutiny** - implies that bodies and selves are always taken for granted before onset of disease this can be disrupted