Caregiver Resilience

An Individual, Family, and Global Health Imperative

Rev. Barbara S. Harris, MDIV, BCC-PCHAC

Palliative Care Chaplain,
Spiritual Care Team Lead

Legacy Salmon Creek Medical Center, Vancouver, WA

Objectives

Based on the resilience in caregiving literature, participants will be able to,

- Describe the scope of **long-term caregiving_as an important global public health issue, associated health risks, health effects, and moral distress;**
- Identify **caregiver-targeted strategies and modalities**, **to promote caregiver resilience**;
- Learn the **vital shift from individual- to family-caregiving, involving the whole family in adapting and moving forward together.**

Caregiver & Family Resilience: Significant personal interest

My mother-–diagnosed at age 47 with Non-Hodgkins lymphoma

Caregiving integral to our family.
How about yours?

Individual resilience: *capacity* of an individual to adapt during hardship and *ongoing significant life stressors* (Bonanno, 2004)

Family resilience *-- dynamic process* involving whole families in <u>leveraging strengths</u> to adapt (Xu & Lin, 2015)

Long-term Caregiving: Global Health Issue

- **349 million** “care-dependent”
- Caregiving – **informal, mostly unpaid**
- **Mostly women:** >23.7 hrs./wk; 21% > 41 hrs.
- **Increasing:** 43.5 million –53 million in U.S. (National Alliance for Caregiving, 2020)
- **24%** FCs dementia pts (assist **> cg hrs./wk**; **> ADLs**) (Dias et al. 2015)

Health Risks of Long-term Caregiving

36% rate their situation as “highly stressful”

23% report fair to poor health (National Caregiving Alliance, 2020)

- **Negative impact on general health** (James et al., 2020)
- Increased **mortality and morbidity** risk (Bom, Bakx, Schut et al., 2019)
- Stroke FCs: anxiety, depression, exhaustion, hopelessness, fatigue (Morais et al., 2012), social isolation (Yu et al., 2013); financial problems (Gok Ugur & Erci, 2019).

Health Effects of Long-term Caregiving

FCs -moderate to advanced dementia

- **Moral distress** and **conflicting "moral obligation"**
- **Increasing burden of care**
- ***Chronic*** psychological and physical **symptoms:**
    a. **Decrease in well-being and life satisfaction**
    b. **Loss and grief** (Acton & Kang,2001); **progressive, ambiguous loss** (Boss, 1999), **disenfranchised grief**

Long-term Caregiving Distress

Cancer Patient-FC Dyad
    Distress, Unmet Needs

- **Who's more distressed?**
- **Cancer context**
- **10 or more Unmet Needs**
    a. Health services
    b. Disease-related information
    c. Emotional support re: fears

(Sklenarova et al., 2015)

Long-term Caregiving Moral Distress

FCs Advanced Cancer — High caregiver burden -- substitute decision-making…*lingering doubt and regret (related to decisional burden) months or even years after pt dies…* (Hamano et al., 2018)

FCs Advanced Cancer – two paths of ethical distress:

1. Difficult decision-making
2. When no decision was to be made (no options)

(Ullrich et al., 2020)

Long-term Caregiving Moral Distress

1. **Difficult decision-making**
    - differing needs
    - interpreting pt’s wishes (communication)
    - unprepared for consequences
    - intra-role conflicts
2. **When no decision was to be made** (no options)…
    - moment of finality
    - rapid disease progression
    - FC left out of patient decision-making: *a fait accompli*

…left them feeling powerless, overrun…

Long-term Caregiving: Averting Moral Distress

- **Acceptance/finding closure** prevented moral residue

  * key: **FC realizing –best effort**

- External Preventive Factors: **time, information, social** and **physician support**

  *****empathy, acknowledgment, validation** of emotions*

  (Ullrich et al., 2020)

- **Good communication skills** (team)
- **Involving ethicists** (Orr et al., 1996)
- **Accepting relationships** (Bristowe, Marshall & Harding, 2016)

Caregiver Moral Distress in the ICU

Speaking for the Dying: Ethnographic research—two years (urban hospital ICU) observing day-to-day decision-making by surrogates and family speaking for pts… (Shapiro, 2019)

- **“Hold life and death in their hands”**
- **Improvising trajectories:** rarely a single decision; learning as they decide –high stakes uncertainty

Caregiver Moral Distress in the ICU

A. **Patient's diagnosis is uncertain-** clinical team is advocating for more interventions *against* family resistance, including concerns about cost

"*But I think I would want her to have the chance.*" Sr. neurologist

Family asks, "*At what cost?*"

Q: Who pays what price for that chance? In what currency?

(Frank, 2022)

Doctor responds: *"Whatever Medicare paid for the first surgery…"*

Caregiver Moral Distress in the ICU

B. Sr. physician tells his residents: *"Our job is to do the impossible."*

What are the effects of magical thinking? (Shapiro, 2019)

C. Case where surrogates appear indifferent to suffering "…go ahead and CODE her, she's dying anyway."

- When surrogates appear indifferent to suffering… **Speculation on motives of surrogates risks saying more about the speculators.**
- On the other side of these relationships—**moral distress** (Frank, 2022)

Caregiver Moral Distress in the ICU

Speaking for the Dying (Shapiro, 2019)

D. "***They're going to say I killed him.***" Niece POA caught in the middle

Epilogue:

*Realistic: "…**be realistic** about (ICU…medicine) its promise."* (Shapiro, 2019)

(Shapiro) "***It's a perfect storm***. *Too many people believe in miracles…and the claims of multiple costs…are too easily deferred, dismissed…"*

"(Shapiro imagines) ***no prospects of preventing moral distress****, only some mitigation…"* (Frank, 2022)

Caregiver Moral Distress in Pediatric Illness

“Morally undesirable involvement…”

1) Intrapersonal

- Compromised
- Constrained
- Unable to shield their child…failing others; *“no one is getting what they need”*

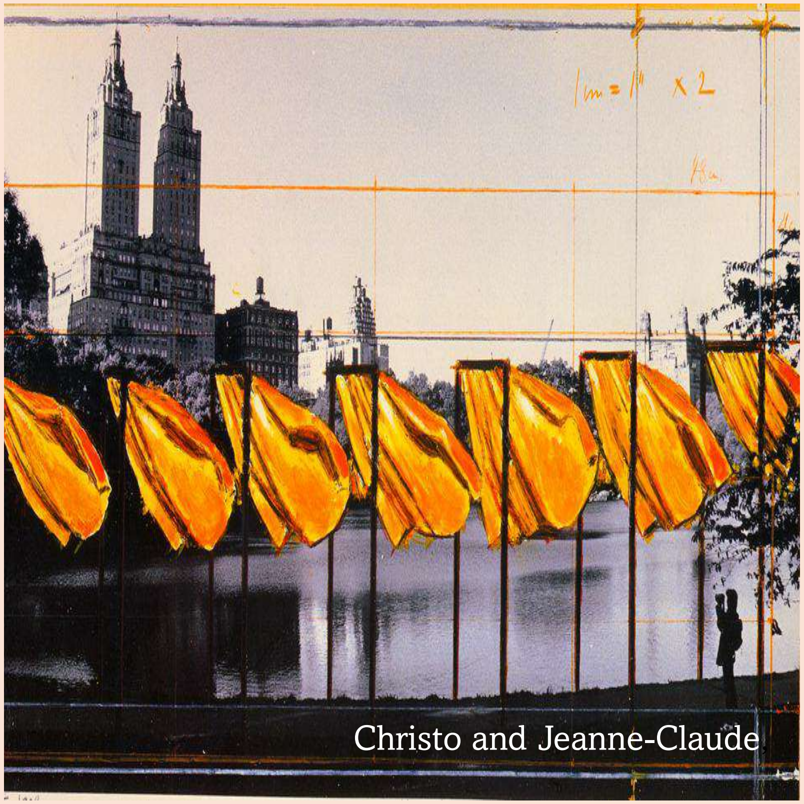
2) Interpersonal

3) Spiritual/existential- - *Religious, Spiritual, Life Philosophy* (RSLP): antecedent or buffer; 60-80% FCs spiritually distressed

Unmet religious and spiritual needs-- poorer psychological QOL (Winkelman et al., 2011)

Caregiver Resilience-Enhancing Modalities

- **Psychoeducation & Support Group**
- **Coaching**
- **Meditation**
- **Mindfulness-based interventions**
- **CBT-based interventions**
- **Spirituality**



Christo and Jeanne-Claude

“FCs can demonstrate resilience in the face of care-giving related stressors and burden.” (Chi et al., 2024)

Caregiver Resilience-Enhancing Modalities

Psychoeducation-Support Group (Inci & Temel, 2016)

- **10 sessions, 5 weeks; 5 education (90mins.), 5 social support (60 mins.)** group; **FCs of stroke patients**
- **Education:** Introduction to stroke; FC burden; care of stroke patients; stress & coping; intra-family interaction
- **Support group**: Socializing; sharing challenges, expressing feelings about caregiving; problem-solving

Results: > FCs resilience, > family resilience

Coaching (MacCourt et al., 2017)

- **6 (grief) sessions** (1/1.5 hr), **6 weeks**; **FCs of dementia patients**

Results: > FCs resilience, empowerment, coping; < grief

Caregiver Resilience-Enhancing Modalities

Meditation (Pandya, 2019)

- RCT- **FCs of Alzheimer patients**; **5-year** study, **45 min. weekly class sessions & *at-home practice***

Results: > resilience, < perceived FC burden, > FC self-efficacy; (most effective for FCs Hindu; attended 75% classes & 75% at-home practice); *need for addressing cultural, education, employment differences*

Mindfulness-based Resiliency Training (MBRT) (Stonnington et al., 2016)

- Single-group**, *six-week MBRT*,** 6 weekly sessions, **FCs of organ transplant patients** - mindfulness training, yoga and education

Results: < stress, depression, anxiety; resilience increased -not statistically (from 0 to 6 weeks; and at 3 months post)

Caregiver Resilience-Enhancing Modalities

CBT-based intervention (McCann et al., 2017)

- 8-week RCT of guided self-help (cognitive behavioral bibliotherapy) for patients with depression (D) and FCs

  1) **D overview**, encouraging **physical activity** (PA)
  2) **Social contact + PA**
  3) **Discerning thinking and feeling**
  4) **Changing neg thought patterns**
  5) **Healthy living, social support + behavior change** help overcome D
  6) Equip improved sleep and sustainable favorable thoughts, behaviors, and emotions
  7) **PMR progressive muscle relaxation** to < stress
  8) Emphasizing **learned skills in thought challenging** to negotiate difficult events

Results: > patient & FCs resilience (at 8 weeks and 12-week follow-up)

Caregiver Resilience-Enhancing Modalities

"Addressing FCs spiritual needs is crucial for enhancing well-being…"
(Uzun et al., 2024)

Spirituality ≠ religion – often conflated, like Palliative Care (PC) and Hospice

- ***dynamic, intrinsic aspect of humanity***
- **meaning, purpose, and transcendence**
- **relationship to self, family, others…nature, the significant or sacred**
- **beliefs, values, traditions, practices** (Puchalski et al., 2014)

- **Pediatric Illness—**5 themes SR/E—(ages 5-17, parents, siblings) 1) fully living; 2) meaning and legacy; 3) uncertainty about future; 4) determination to survive; 5) accepting/fighting the future; role of religion.
- **"Eliciting spiritual concerns may help to identify the things that can support a meaningful life."** (Scott et al., 2023)

Caregiver Resilience-Enhancing Modalities

Spirituality in FCs PC Patients: Sense-making, belonging, beliefs, relationships to significant/sacred

Spiritual Needs (SNs) of FCs: love, positivity, meaning, hope, gratitude, relationship with God and others, transcendence, religious rituals, support, communication, processing guilt; guidance & preparation for death

Fulfillment SNs: helped FCs **progress through grief**…>life satisfaction, power and peace, ***transforming the act of caregiving --*** rewarding and meaningful experience (Uzun, Basar, & Saritas, 2024)

Spirituality in Stroke Survivors & FCs: > Quality of Life (QOL) ; < anxiety and depression; belief Higher Power –better mental health (Ambrosca et al., 2024) (meta-analysis of 37 studies); emotionally protective (Johnstone et al., 2008).

Resilient Families – How They Cope

2.) **Family belief system**: buffer, protective in coping

(Kuang et al., 2022) (14 studies, 8 countries, 11 illnesses)

2.1) Rational appraisal

‘It is what it is, *and I don’t think it’s a disaster. It’s life.’* (Reader et al., 2020)

‘I used to wonder why I had cancer. Now I understand *that since* ***cancer is part of my body, I try to use this time to experience life,*** learn to be kind to people around me, and discover the beauty of life.’ (Kuang et al., 2022)

Resilient Families – How They Cope

2.2) Family positive belief from spirituality…hope, security through faith (Kuang et al., 2022)

"I have something, someone other that what we can see or touch, that I can meditate, commune, pray with or to, that I derive some meaning from." (Jones et al., 2018)

… and belief from positive traits (optimist)

Then I tell myself, this is what is in front of us. We will try to find a solution… (Gauvin-Lepage, 2019)

2.3) Dyadic transmission of positive attitude: Patients and FCs report -- partner's attitude affected them.

"…I have to keep it going for him." (Reader et al., 2020)

Resilient Families – How They Cope

3.1.) Proactive coping in patients and FCs: Active learning (accumulate knowledge, experience + improved skills)

3.2) Family resources and practical mutual support

Stable economic support

Flexibly adjusting roles *"My older kids help out when they need to, with baby sitting or whatever…"* (Deist & Greeff, 2017)

Close family relationships

Family problem-solving efforts

Resilient Families –How They Cope

4.) External support -- extremely important (Kuang et al., 2022)

4.1) Substantive services—society and institutional support can reduce pressure

4.2) Sound emotional support network: more social support—better they adapted

"Emotionally, it's a strain, and ***there's no way you can do it alone.*** *My advice to anybody would be to* ***use whatever help you can get. Don't push anyone away****; the more hands, the better."* (Deist & Greef, 2017)

4.3) **Information and skills training**: Per an RN, *"If you don't have information about it, you don't know how to tackle it. You don't know how to deal with it."* (Reader et al., 2020)

Family Resilient Adaptation Indicators

5.) Resilient adaptation indicators

5.1) Personal growth and value: *the disease made them grow,* discover who they truly were, accept the reality of the disease and actively cooperate with treatment.

"I sort of see, what happened to me, not as a negative event…a part of me…my life…that's what was destined for me in the story of my life. And I am trying to deal with it and live on with it." (Schembri Lia & Abela, 2016)

5.2) Family bonds, strength and positive expectancy

Relying on **encouragement and inner strength,**

families *take action* to start a new life by *adjusting their direction and goals*.

"We're determined that the (SCI's) not going to mess up our lives." (Jones et al., 2018)

Family Resilience: Summary Priorities

1) **Relieve Secondary and Primary Stressors** 1.1) caregiver physical burden; 1.2) dyadic negative emotion and stigma; 1.3) family relationship tension; 1.4) economic stress; 1.5) isolation (Kuang et al., 2022)

2) **Provide Family Counseling –positive cognition, family belief system and function** (Saltzman, 2016)

3) **Strengthen Support Systems**

4) **Involve Ethicists** (Orr et al., 1996)

Family Resilience: Summary Priorities

5) Engage Resilience-Enhancing Modalities

CBT, Psychoeducation & Support Group, Meditation, Mindfulness (MBRT), Coaching for Grief, Spirituality

6) Provide Information, Empathy, Acknowledgment, Validation

7) Create Accepting Relationships

8) Communicate Skillfully

9) Address Spiritual Needs-- to engage what matters

*"Emotionally, it's a strain…**there's no way you can do it alone…"***

Let's Do Our Part…

References

- Acton, G. & Kang, J. (2001). Interventions to reduce the burden of caregiving for an adult with dementia: A meta-analysis. *Research in Nursing & Health 24*(5):349-360. https://doi.org/10.1002/nur.1036
- Ambrosca, R., Bolgeo, T., Zeffiro, V., Alvaro, R., Vellone, E., & Gianluca, P. (2024). The role of spirituality in stroke survivors and their caregivers: A systematic review. *Journal of Religion and Health 63*:3501-3531. https://doi.org/10.1007/s10943-024-02029-0
- Bom, J., Bakx, P., Schut, F., & Van Doorslaer, E. (2019). The impact of informal caregiving for older adults on the health of various types of caregivers: A systematic review. *The Gerontologist, 59*(5), e629-e642. https://doi.org/10.1093/geront/gny137
- Bonanno, G.A. (2004). Loss, trauma, and human resilience: Have we underestimated the human capacity to thrive after extremely adverse events? *American Psychologist*, *59,* 20-28. https://doi.org/10.1037/1942-9681.S.1.101
- Boss, P. (1999). *Ambiguous loss: Learning to live with unresolved grief.* Cambridge, MA: Harvard University Press.
- Bristowe, K., Marshall, S., & Harding, R. (2016). The bereavement experiences of lesbian, gay, bisexual and/or trans* people who have lost a partner: A systematic review, thematic synthesis and modelling of the literature. *Palliative Medicine, 30*(8), 730-744. https://doi.org/10.1177/0269216316634601
- Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience*, *11*(2), 217-228. *https://doi.org/10.31887/DCNS.2009.11.2/hbrodaty*
- Chen, C., Sun, X., Liu, Z., Jiao, M., Wei, W., & Hu, Y. (2023). The relationship between resilience and quality of life in advanced cancer survivors: Multiple mediating effects of social support and spirituality. *Frontiers in Public Health, 11*, 1207097. https://doi.org/10.3389/fpubh.2023.1207097

References

- Chi, N. C., Han, S., Lin, S. Y., Fu, Y. K., Zhu, Z., Nakad, L., & Demiris, G. (2024). Resilience-enhancing interventions for family caregivers: A systematic review. *Chronic Illness*, *20*(2), 199-220. https://doi.org/10.1177/17423953231174928
- Deist, M., & Greeff, A. (2017). Living with a parent with dementia: A family resilience study. *Dementia 16*(1):126-141. https://doi.org/10.1177/1471301215621853
- Dias, R., Santos, R. L., Sousa, M. F. B. D., Nogueira, M. M. L., Torres, B., Belfort, T., & Dourado, M. C. N. (2015). Resilience of caregivers of people with dementia: A systematic review of biological and psychosocial determinants. *Trends in Psychiatry and Psychotherapy, 37*, 12-19. https://doi.org/10.1590/2237-6089-2014-0032
- Ferrell, B., Chung, V., Koczywas, M., Borneman, T., Irish, T. L., Ruel, N. H., ... & Smith, T. J. (2020). Spirituality in cancer patients on phase 1 clinical trials. *Psycho-Oncology, 29*(6), 1077-1083. https://doi.org/10.1002/pon.5380
- Frank, A. W. (Winter, 2022). Moral distress in deciding how others die. *Perspectives in Biology and Medicine 65*(1):59-72. https://doi.org/10.1353/pbm.2022.0003
- Gauvin-Lepage, J. (2019). Traumatic brain injury in adolescence and the family resilience process: A case study. *SAGE Open Nursing, 5,* 2377960819848231. https://doi.org/10.1177/2377960819848231

References

- Gok Ugur, H., & Erci, B. (2019). The effect of home care for stroke patients and education of caregivers on the caregiver burden and quality of life. *Acta Clinica Croatica*, *58*(2.), 321-332. https://doi.org/10.20471/acc.2019.58.02.16
- Greenberg, J. & Jordan, S. (2008). *Christo and Jeanne-Claude: Through the gates and beyond*. NY: Roaring Brook Press.
- Hamano, J., Morita, T., Mori, M., Igarashi, N., Shima, Y., & Miyashita, M. (2018). Prevalence and predictors of conflict in the families of patients with advanced cancer: A nationwide survey of bereaved family members. *Psycho-Oncology, 27*(1), 302-308. https://doi.org/10.1002/pon.4508
- Hu, P., Yang, Q., Kong, L., Hu, L., & Zeng, L. (2018). Relationship between the anxiety/depression and care burden of the major caregiver of stroke patients. *Medicine*, *97*(40), e12638. https://doi.org/10.1097/MD.0000000000012638
- İnci, F. H., & Temel, A. B. (2016). The effect of the support program on the resilience of female family caregivers of stroke patients: Randomized controlled trial. *Applied Nursing Research, 32*, 233-240. https://doi:10.1016/japnr.2016.08.002
- James, C., Walshe, C., & Froggatt, K. (2020). Protocol for a systematic review on the experience of informal caregivers for people with a moderate to advanced dementia within a domestic home setting. *Systematic Reviews, 9*, 1-8. https://doi.org/10.1186/s13643-020-01525-0
- Johnstone, B., Franklin, K. L., Yoon, D. P., Burris, J., & Shigaki, C. (2008). Relationships among religiousness, spirituality, and health for individuals with stroke. *Journal of Clinical Psychology in Medical Settings, 15*, 308-313. https://doi.org/10.1007/s10880-008-9128-5
- Jones, K. F., Dorsett, P., Simpson, G., & Briggs, L. (2018). Moving forward on the journey: Spirituality and family resilience after spinal cord injury. *Rehabilitation Psychology, 63*(4), 521. https://doi.org/10.1037/rep0000229

References

- Kuang, Y., Wang, M., Yu, N. X., Jia, S., Guan, T., Zhang, X., ... & Wang, A. (2023). Family resilience of patients requiring long-term care: A meta-synthesis of qualitative studies. *Journal of Clinical Nursing, 32*(13-14), 4159-4175. https://doi.org/10.1111/jocn.16500
- MacCourt, P., McLennan, M., Somers, S., & Krawczyk, M. (2017). Effectiveness of a grief intervention for caregivers of people with dementia., *OMEGA-Journal of Death and Dying 75*(3), 230-247. https://doi.org/10.1177/0030222816652802
- McCann, T. V., Songprakun, W., & Stephenson, J. (2016). Efficacy of a self-help manual in increasing resilience in carers of adults with depression in Thailand. *International Journal of Mental Health Nursing*, *25*(1), 62-70. https://doi.org/10.1111/inm.12178
- McCann, T. V., Songprakun, W., & Stephenson, J. (2017). Effectiveness of a guided self-help manual in strengthening resilience in people diagnosed with moderate depression and their family caregivers in Thailand: A randomised controlled trial. *Issues in Mental Health Nursing*, *38(8*), 655-662. https://doi.org/10.1080/01612840.2017.1313913
- Mooney-Doyle, K., & Ulrich, C. M. (2020). Parent moral distress in serious pediatric illness: A dimensional analysis. *Nursing Ethics, 27*(3), 821-837. https://doi.org/10.1177/0969733019878838
- Morais, H. C. C., Soares, A. M. D. G., Oliveira, A. R. D. S., Carvalho, C. M. D. L., Silva, M. J. D., & Araujo, T. L. D. (2012). Burden and modifications in life from the perspective of caregivers for patients after stroke. *Revista Latino-americana de Enfermagem, 20*, 944-953. https://doi.org/10.1590/S0104-11692012000500017

References

- Munoz, A. R., Salsman, J. M., Stein, K. D., & Cella, D. (2015). Reference values of the functional assessment of chronic illness therapy-spiritual well-being: A report from the american cancer society's studies of cancer survivors. *Cancer, 121*(11), 1838-1844. https://doi.org/10.1002/cncr.29286
- National Alliance for Caregiving. (2020). *Caregiving in the U.S.* https://www.caregiving.org/research/caregiving-in-the-us/
- Orr, R. D., Morton, K. R., deLeon, D. M., & Fals, J. C. (1996). Evaluation of an ethics consultation service: Patient and family perspective. *The American Journal of Medicine, 101(2*), 135-141. https://doi.org/10.1016/S0002-9343(96)80067-2
- Paidipati, C. P., Foxwell, A. M., Mooney-Doyle, K., Tiller, D., Pinto-Martin, J., & Ulrich, C. M. (2023). Caregiver perspectives on the benefits, burdens, and moral distress of participation in cancer clinical trials. *Journal of Family Nursing, 29(1*), 89-98. doi: 10.1177/10748407221098187
- Pandya, S. P. (2019). Meditation program enhances self-efficacy and resilience of home-based caregivers of older adults with Alzheimer's: A five-year follow-up study in two South Asian cities. *Journal of Gerontological Social Work*, *62*(6), 663-681. https://doi.org/10.1080/01634372.2019.1642278
- Puchalski, C. M., Vitillo, R., Hull, S. K., & Reller, N. (2014). Improving the spiritual dimension of whole person care: Reaching national and international consensus. *Journal of Palliative Medicine*, *17*(6), 642-656. https://doi.org/10.1089/jpm.2014.9427
- Reader, S. K., Pantaleao, A., Keeler, C. N., Ruppe, N. M., Kazak, A. E., Rash-Ellis, D. L., ... & Deatrick, J. A. (2020). Family resilience from the perspective of caregivers of youth with sickle cell disease. *Journal of Pediatric Hematology/Oncology*, *42*(2), 100-106. https://doi.org/10.1097/MPH.0000000000001682

References

- Scott, H. M., Coombes, L., Braybrook, D., Roach, A., Harðardóttir, D., Bristowe, K., ... & Harding, R. (2023). Spiritual, religious, and existential concerns of children and young people with life-limiting and life-threatening conditions: A qualitative interview study. *Palliative Medicine*, *37*(6), 856-865. https://doi.org/10.1177/02692163231165101
- Shapiro, S. P. (2019). *Speaking for the dying: Life-and-death decisions in intensive care*. University of Chicago Press. Schembri Lia, E., & Abela, A. (2016). Not broken but strengthened: Stories of resilience by persons with acquired physical disability and their families. *Australian and New Zealand Journal of Family Therapy*, *37*(3), 400-417. https://doi.org/10/1002/anzf.1156
- Sklenarova, H., Krümpelmann, A., Haun, M. W., Friederich, H. C., Huber, J., Thomas, M., ... & Hartmann, M. (2015). When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. *Cancer, 121*(9), 1513-1519. https://doi.org/10.1002/cncr.29223
- Stonnington, C. M., Darby, B., Santucci, A., Mulligan, P., Pathuis, P., Cuc, A., ... & Sood, A. (2016). A resilience intervention involving mindfulness training for transplant patients and their caregivers. *Clinical Transplantation*, *30*(11), 1466-1472. https://doi.org/10.1111/ctr.12841
- Ullrich, A., Theochari, M., Bergelt, C., Marx, G., Woellert, K., Bokemeyer, C., & Oechsle, K. (2020). Ethical challenges in family caregivers of patients with advanced cancer – a qualitative study. *BMC Palliative Care*, *19*, 1-13. https://doi.org/10.1186/s12904-02000573-6

References

- Uzun, U., Başar, S., & Saritaş, A. (2024). Spiritual needs of family caregivers in palliative care. *BMC Palliative Care*, *23*(1), 256. https://doi.org/10.1186/s12904-024-01589-y
- Weigel, C. (2019). Caregiving and moral distress for family caregivers during early-stage Alzheimer's disease. *IJFAB: International Journal of Feminist Approaches to Bioethics*, *12*(2), 74-91. https://doi.org/10.3138/ijfab.12.2.05
- World Health Organization. (2017). Integrated care for older people: Guidelines on community-level interventions to manage declines in intrinsic capacity. In Integrated care for older people: Guidelines on community-level interventions to manage declines in intrinsic capacity. https://iris.who.int/bitstream/handle/10665/258981/9789241550109-eng.pdf?sequence=1
- Winkelman, W. D., Lauderdale, K., Balboni, M. J., Phelps, A. C., Peteet, J. R., Block, S. D., ... & Balboni, T. A. (2011). The relationship of spiritual concerns to the quality of life of advanced cancer patients: preliminary findings. *Journal of Palliative Medicine*, *14*(9), 1022-1028. https://doi.org/10.1089/jpm.2010.0536
- Xu, Y., & Lin, D. (2015). Family stress and adolescents' depression, loneliness and happiness: The compensatory and moderating roles of family resilience. *Psychological Development and Education, 31*(5), 594-602. https://doi.org/10.16187/j.cnk.issn1001-4918.2015.05.11
- Yu, Y., Hu, J., Efird, J. T., & McCoy, T. P. (2013). Social support, coping strategies and health-related quality of life among primary caregivers of stroke survivors in China. *Journal of Clinical Nursing*, *22*(15-16), 2160-2171. https://doi.org/10.1111/jocn.12251