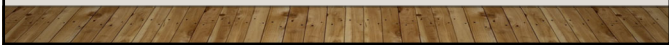


CHANGING DYNAMICS: STRENGTHENING FAMILY RELATIONSHIPS AS PEOPLE AGE

MENTAL HEALTH ISSUES IN LONG-TERM CARE

CHRISTOPHER SPARKS, LISW

I Have No Financial Conflicts Of Interest To Disclose




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Getting Acquainted


Couples face a myriad of challenges:

- Poor communication,
- Inattention to the other's needs,
- Lack of intimacy,
- Disagreements about parenting,
- Financial stress,
- Substance Abuse,
- Infidelity...



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Practice Trends in Couple's Therapy



Couple's and marriage counseling at the CMHC in Waterloo, practice trends.

- Couples where one or both had a serious mental health diagnosis.
- Same sex couples, trans couples, adult parent/child, and
- Older couples married over thirty or even forty or more years.

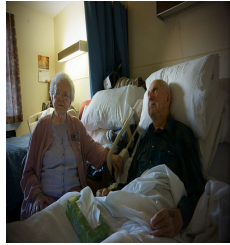
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Challenges Facing Aging Couples

The American Community Survey, data from the US Census:

- Considers someone to have a disability if they reported vision, hearing, cognitive, ambulatory, self-care or independent living difficulty.
- Annually, during the 2015-2019 period, about 18.2 million older people, or about 36.0% of people ages 65 and older, reported at least one disability.
- Disability can create caregiving needs.

US Census Bureau



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Caregiving in America

Caregiving: help with activities of daily living, paying bills, shopping, or transportation. It also includes the provision of emotional support and managing chronic disease or disability.

- In the US, middle-aged children and older adults provide a substantial portion of care.
- Caregiving demands can impact a person's ability to work, maintain essential social connections, and can even affect their physical and mental health.



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Caregiving in Iowa

- In Iowa 16.8% of adults age 45 or older reported being a caregiver to friend or family member.
- Of those people, 10.5% of them reported struggling emotionally with stress and depression.
- Over 37% of caregivers in Iowa reported having serious health problems themselves, like heart disease, cancer, COPD, etc.
- In Iowa nearly 18% of adults age forty-five or older expect to be caregivers in the next two years.



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Helping Couples Navigate Long-Term Care



The decision for a loved one to go into LTC elicits a myriad of emotions:

- stress, guilt,
 - anger, anxiety,
 - depression,
 - and continuing burden
- Spouse roles shift from provision of hands-on care to that of visiting, monitoring care, and serving as an advocate for their institutionalized relative.

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Challenges to Successful LTC Placement

1. Coming to grips with group services. Activities, meals, etc. are geared to a common set of interests and abilities.
2. Relinquishing control.
3. Staffing instability.
4. Confusion about family participation/roles.
5. Surrendering terminal life goals.



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Challenges following couples into LTC

Complicating Factors:

- Communication
- Time together and intimacy,
- Sexuality,
- Role changes,
- Surrendering terminal life goals,
- Any significant and unaddressed relationship problems (abuse, substance abuse, infidelity, neglect, etc.).



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Couple's Transitioning to LTC

- Trust is an overarching issue for families placing a loved one in LTC setting.
- Trust can be built over time.
- Families have to get to know staff.
- Scheduling and workforce challenges make this harder.
- Families want an assurance that staff are capable *and* decent human beings.
- Families struggle to understand the regulatory and organizational demands of the facility.



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Couple's Transitioning to LTC, continued



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Threading the needle on family involvement:

- Personal care and ADL assistance,
- Activities outside the facility,
- Managing finances,
- Providing social support and companionship,
- Monitoring care and advocating interests of their loved one,
- Providing important and helpful background knowledge on their loved one.

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Supporting Couples after LTC Placement

After placement loved ones often experience ambivalence.

- They feel relief after the stress of providing home care for their partner,
- But they feel responsible for their partner's having to go into a nursing home
- Losing control, it can be difficult for loved ones to let go,
- Conflicts over care expectations.
- Family can attempt to control care staff and show a strong desire to be involved in their loved one's care.



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Supporting Couples after LTC Placement



Success is more likely if families receive an orientation, tour, and meet key staff. And if the facility:

- Defines pathways for families to communicate with staff and leadership.
- Builds trust: studies suggest it's critical for spouse and resident satisfaction.
- Upholds clear standards.
- Responds to and resolve problems.

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Supporting Couples after LTC Placement

Redefining the caregiver role:

- Help families transition from hands-on care provision to a focus on spending time and offering emotional support.
- Families negotiate changes in roles with staff, which requires some finesse and confidence on the part of staff.
- These changes can be very challenging for families.



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Supporting Couples after LTC Placement

Care Expectations: the dilemma over care standards.

- Facility versus family care.
- Diligence, responsiveness, and reasonable expectations are critical.
- "Little things" can be quite important such as personal appearance, missing clothing, food preferences not being honored, or not showing interest or investment.
- Families often are concerned about access to medical treatment and medical staff competence.



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Supporting Couples after LTC Placement

- *Communication*: getting needed information and communicating concerns.
- *Psychosocial Factors*: Boredom, loneliness, and guilt.
- *Dealing with the deterioration of the loved one*: challenging for families to witness physical and cognitive decline.
- *Organizational Barriers*: staffing challenges including understaffing and changing faces. Staff who are unfriendly. Physical conditions not meeting expectations.



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Strengthening Couple and Family Relationships

- Support Role Transition from Caregiver to Supportive Spouse.
- Visit Structure and Activities: How do people spend time together?
- Allow Space and Time for Intimacy: Closeness, comfort, shared feelings, shared interests, friendship.



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Supporting Couples after LTC Placement, bigger problems...

1. Improving Communication.
2. Resolving long-standing conflicts.
3. Rediscovering time together and intimacy.
4. Renegotiating the relationship agreement.
5. Finding the next chapter in their story.
6. Managing extended family problems.



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Strengthening Couple and Family Relationships

Relationship attributes that strengthen couples:

- **Flexibility:** ability to adapt to the challenges of long-term care placement, separation, and disruption. Disruptive transitions require a willingness to change, balanced by efforts to stabilize routines.
- **Connectedness:** Couples that balance needs for intimacy and mutual support with respect for separate pursuits and individual differences.
- **Social and Economic Resources:** Couples with good and reliable familial and social support and adequate financial resources function better after long term care placement.

(John Rolland's Family System Illness Model, adapted)

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Strengthening Couple and Family Relationships



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Communication is essential for couples in transition:

- **Clarity:** clear and consistent messages in word and action. Clarify any confusing information. Be truthful.
- **Emotional Expression:** the couple (and family) should share emotional struggles honestly (e.g., fear, anger, disappointment, grief, etc.).
- Couples need to **share affirmative feelings:** joy and excitement, love, appreciation, gratitude, humor, fun, etc.
- **Collaborative Problem Solving:** couples need to solve problems together, share decision making, focus on goals, work to be proactive, and prepare for future challenges.

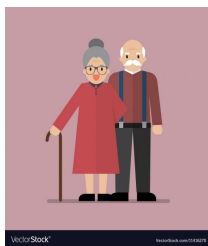
(John Rolland's Family System Illness Model, adapted)

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In Closing:

- Under the best of conditions, couples and families face trials and tension.
- Physical and cognitive decline and family members becoming caregivers puts stress on families.
- The decision to seek long-term care for a loved one is difficult and results in a complex mix of emotions.
- Helping the couple adapt to long-term care placement and continue to function as a couple results in dramatically increased satisfaction. It's largely uncharted territory.



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Questions?



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