

From Home to Retirement Home Use of Case Stories to Examine lived Experiences of Persons with Dementia During Transition

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Background

- "Feeling at home" is important for PWD who experience many losses, discontinuities & disruptions
- PWD often have to face the reality of multiple housing transitions
- Growing number turning to retirement residences when living at home is no longer an option



Qualitative Prospective Study

- To learn about meanings, decision making processes, support needs, & outcomes of relocation to a retirement residence from perspective of PWD & their family caregivers
- In-depth interviews with PWD & family caregivers over a period of 10 months:
 - 2 months before relocation
 - 2 months after relocation
 - 6 months after relocation



Objective

- Use of "actual" case stories to illustrate selected findings & concepts from research
- Clinically relevant examples to examine complexities, dilemmas, lived experiences, & varied outcomes

"The **HOUSE** is a nice **HOME**"

Profound meaning of
"home" & household
objects



Aminzadeh et al. (in press).
Journal of Gerontological Nursing.

- Prospect of separation from home brought to the surface strong attachment to home:
 - **Constancy, Continuity, Connection, Comfort, Choice, Control, Competence**



Home as a Paradox

"Our home became a bit of a chore"

- Gradual loss of positive experiences associated with living at home:
 - **Source of frustration, conflict, disappointment, dependency, intrusion, & isolation**



Tension Between Competing Needs



Meaning of Relocation

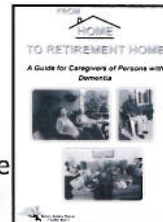
- *"It's the end of an active & independent life as created by God"*



Aminzadeh, F. et al. (2009).
Ageing & Mental Health

From Home to a Retirement Home: A Guide for Caregivers of PWD

- Why a move may become necessary
- How to make the decision
- What emotions to expect & how to cope
- How to choose the right place
- How to prepare for the move
- How to support the person with dementia after the move



Case Study #1 HOME ALONE WITH DEMENTIA



Discussion/ Critical Analysis:

- Key elements shaping response?
- Process & outcomes optimized?
- Support needs?
- Lessons Learned?
-



- 87 year old widow living alone in a well decorated condo for the past 11 years
- Dx: mixed AD/VaD (Aricept)
- MMSE 23/30; CDR 1; supervision +/- assistance needed for most IADL
- Physical health/safety concerns: inadequate nutrition (diabetic: hypoglycemic episodes); missed medications for several months; burned a hole on kitchen floor; rotten food in fridge; etc.
- MOW; private PSW 2hr/daily X5 (ineligible for CCAC); son & dtr visiting regularly

Initial Reaction

- *"She kept saying 'now, you've to go to a retirement home' "*
- ***I said: 'well I don't feel ready, I've a daughter & a son that will help me whenever... I just like it so much here'...."***



Contemplation & Exploration

- *"My son thinks I'd be better off there. He thought it was too much for me to go to Loeb's, winter coming...."*
- ***"But, I'm lucky I've strong legs... I've a walker, & of course, I enjoy it."***

Self-Scrutiny & Life Review

- *"He thinks at my age I'd be better in a retirement home **with people....**"*
- *"Since my husband died, I've been what you might call a '**loner**' ... this is very quiet, I knit, I've birds... well, it might be a little **difficult getting used to all the people around, there are some that are irritating...** I don't like eating with other people...."*

Points of Divergence

Caregivers

- Proactive approach in anticipation of future decline
- Emphasis on deficits, vulnerabilities, dependencies, & risks
- Focus on burden of living at home & attractions of RR living

PWD

- Present-oriented temporal focus
- View of self as relatively healthy, competent, self-reliant
- Focus on supportive function of home & losses associated with relocation

Salient Meanings of Home

- A place of retreat, solitude & rejuvenation
- A site for expression of functional competence & engagement in meaningful ADL & social ADL
- A repository of memories of life history



Multiple "Voices"

- PWD: "she (dtr) doesn't want me to go from here, because I'm near here, she pops over every other day if she wants..."
- Son: "It means my sister & I won't inherit any money. But, I'm more concerned about her that me getting the money... **I'm assuming it'll lighten my load. I can't deny that.**"

Decisional Conflict & "Voluntary Submission"

- "I said to my daughter 'look, this is difficult for me, he wants one think & you don't want it'...**If I had a choice I'd love this place, I'd like to stay here...but for years, he's always been there for me...**"



Embracing Decision

- Moved to a small studio in a reasonably priced RR in rural area
"This place I'm going is very nice... there's a farm there ... that's the kind of thing I like..."



Post Relocation Adjustment: 2-Month Follow-Up

- Son visits once a week & plans to "take off" for a week to the Caribbean:
"I wish I had done it earlier... They give her pills, they puree her meals... the only thing is she doesn't initiate... but I'm sure she'll be forced to get involved, other than just sit in her room..."

Place Integration

- **"The move was hard. Once I go here, I thought I like the other place, of course..."**
- **"But, I'm quite happy here... it's quiet ... I walk a lot, I go around here & I see big ducks... I'm not really a people person... I don't mind, I've my knitting to do..."**
- **"Let's put it this way, I've been here two months, not one person has come & said: 'will you come & visit me?'..."**

6-Month Follow-Up

- Inadequate diabetes management (nausea, diarrhea, wt loss, "passed out", etc.):
 - Son: "she seems to be eating well... she insists on having ice cream three times a day... I don't want to interfere..."
- "Big lump on her cheek size of a cauliflower"

Lonely in Crowd?

- "She won't make any effort to partake in the activities... she sits by herself at meals... **she prefers her own company...**"
- "I don't know whether other ladies had complained or whatever.... Because, when she eats if she detects any sort of lump, she has to spit that out...."
- "**she talks about our house where I grew up ... she lived there for 50 years. Like that was her whole life, getting married, having 2 or 3 kids....**"

Longing for Home: A Place of Connectedness/Affiliation

- "Well, I like this room. **I don't mind being here, because I look around my things....**"
- "I'm pretty much alone here... All these apartments, **they're all friendly, but nobody says 'well, come on in'...**"
- "When I'm in bed, I think about what I did, I had a cat & a dog that would sleep on the bed & my husband"

Secondary Cognitive Coping: Resilience

- "I miss my apartment, but I mean, this is where I'm, what's the use of getting miserable... **If this is the way my life is, I'm not going to not like it...**"

Discussion/ Critical Analysis:

- Key elements shaping response?
- Process & outcomes optimized?
- Support needs?
- Lessons Learned?
-



Case Study #2 *Two Lives In Transition*



- 82 year old woman Living with her husband & dog in a spotless 2-storey house
- Dx: early AD (Aricept)
- MMSE 26/30; CDR 0.5; Difficulty with more complex IADL
- Cleaning lady weekly; extensive support network of family; active social life
- Physical health/safety concerns: burning pots; fell on stairs, lack of energy:
"I sleep a lot because I'm tired & I think people sleep when they want to turn off all the buttons...."

Initial Reaction

- "My doctor said 'do you think it's time you had a change?' & he sort of put a plus on that thought... **It was too much for us...** my days are full of moving around this house... "



Contemplation & Exploration

- "The place we're going to, everybody we asked says 'it's a nice place. It's the best in Ottawa.' ... "
- "But, a person like myself moving out of this house & going to an establishment like we're going to, **you wouldn't be able to cook again & that's cutting a big slice of your life out...**"

Self-Scrutiny & Life Review

- "Armed Forces has taught me cooperating with groups of people, being part of a group, tolerate other ideas from people... **the Army put you in a position & say, 'Deal with it.'**"

Multiple "Voices"

- Daughter: "She says 'you worked for 80 years, let someone else do it.'... she's helping in a lot of ways, financially & otherwise...."
- Husband: "I noticed it the day when I was in there, **you lose the uh, atmosphere of the younger people**, to keep you active & thinking younger instead of, all these older people, talking about everybody's illnesses"

Decision By Consensus: "Rationalized Alternative"

- Moved to a one bedroom apartment in a luxurious RR in same neighborhood:
"We have a very good existence here. But we need help now...."



Post Relocation Adjustment: 2-Month Follow-Up

- "Right now things are still strange... **the fact that I can't cook a meal, that has made me sad more than anything else...** because the food here is hard to get used to...I don't digest it well...."



**Longing for Home:
Place of Comfort, Privacy, Security,
Enjoyment, Harmony, Order,**

- *"I love privacy... here, the door must be locked all the time because people walk into your apartment... I can't run around with half enough clothes on, there's too many people here... **home to me is a comfortable meal in a comfortable home** & I loved home because I could polish up my home...."*

**Longing for home:
Locus of autonomy, freedom
of action, socialization,**

- **Spouse:** *"It's hard. **I don't like the restriction**, like, you have to sign-in, sign-out, all these things... **I miss interaction with younger people**... you seem to get forgotten... I think because you're in a senior place... it's a different attitude"*

6-Month Follow-Up

- Had "nasty" arguments with the chef: *"That man couldn't cook. I lost about fifteen pounds, I had diarrhea for a month...."*
- Lost earrings: *"They were stolen out of my room... I knew there was no such a thing as privacy there...."*
- Moved to a 2-bedroom condo after 5 mths!

- **PWD:** *"**I was born to be able to cook all my life...** I'd be extremely careful if I had to go to a place like that again...."*

- **Spouse:** *"You get people that are complaining all the time... **They leave an impression of sickness & inability... living here is great you can come & go...** we were fortunate, we were able to get out"*

Discussion/ Critical Analysis:

- **Right housing choice for the couple?**
- **Key elements shaping responses?**
- **How process & outcomes optimized?**
- **Lessons Learned?**
-



Paradox of Residential Living



Success Story!

- *"I'm one of the activities here. I play piano for them. I've been an entertainer all my life... I've made a special friend. He sings along. We've a very pleasant time together. We act like a couple of elderly teenagers..."*



Conclusion

- **Loss of home in old age can carry with it a loss of identity & meaning in life**
- Support older persons efforts to **"age in place"** for as long as this is possible, & when no longer suitable, support their efforts to **"place" themselves** in new living environments (Leith, 2006)



Societal Level Interventions

- Continuous system of care which includes a range of accessible, responsive, flexible, & quality home support services & multilevel affordable supportive housing options
- Evidence on meanings & functions of home to inform design & operation



Individual Level Interventions

- Housing & care recommendations should be person-centered
- Relocation is not a concrete time limited event but ongoing process of adjustment
 - Decision making processes & perceptions strongly influence subsequent adjustment

Pre-Relocation Support

- **Assessment of housing history** (i.e., needs, meanings, wishes, worries, resources, etc.) to make choices that maximize **congruence, continuity, & connection**
- **Emotional support to prepare for transition:**
 - Attentive & empathic listening
 - Reminiscence



Post-Relocation Support: Living in a "Home" vs Living at Home

- Difficulties faced in:
 - Re-creating "home" (transferring sense of "hominess")
 - Re-defining "self" (personal/social identity)



- Dementia can influence appraisal of situation, sense of self-mastery, & adaptive capabilities, in turn, complicating key processes & perceptions that can promote positive outcomes
 - **Proactive planning to maximize agency & self-efficacy**

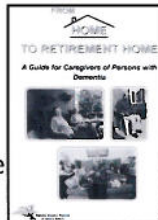


■ Supportive Interventions

- Maximize individuality; **continuity** with past; expression of functional **competence; control** over routines, schedules & private space; **choice** to participate in meaningful solitary & group activities; etc.
- Facilitate **connection**, assess need for support with “social ADL” to navigate social terrain! (assigning a buddy to befriend, meal time matchmaking, private dining room to socialize with friends/family, etc.)

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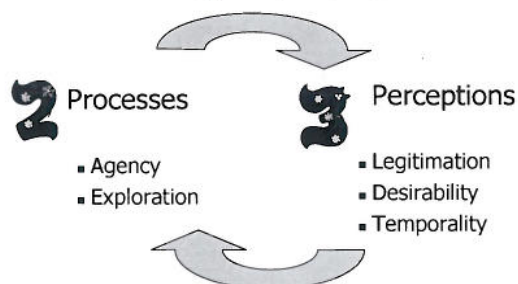
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“Home gains meaning through it’s absence & journeys away” (Moore, 2000)



Key Elements



(Chenitz, 1983, Lurch et al., 2000; Nolant & Grant, 1992; Nolant et al., 1996; Reed et al., 2003)



Response Types

- **Positive Choice**
 - Embracing relocation: perceived as being voluntary, reasonably planned, & mostly desirable
- **Rationalized Alternative**
 - Acceptance of relocation: perceived as being a necessary change that had to be tolerated
- **Forceful Resistance**
 - Adverse reaction to relocation: perceived as being imposed, illegitimate, & undesirable

Relocation Anxiety

- *"Doctors never find anything wrong with me. I feel healthy enough to do everything."*
- *"I didn't like how those young people treat older people... they don't know that **some people, their brain let go**... that's why I'm afraid to go... that thought is against me."*