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The Lived Environment Life Quality Model for institutionalized people with dementia

Le Lived Environment Life Quality Model pour intervenir dans les établissements de soins auprès des personnes atteintes d'une démence

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Mots clés : centré sur le client; établissements de soins; maladie d'Alzheimer; occupation; qualité de vie.

Abstract

Background. There is a need for a conceptual practice model that explicates ecological complexities involved in using occupation to optimize the quality of life of institutionalized people with dementia. **Purpose.** This study aimed to prepare the Lived Environment Life Quality Model, a dementia-specific conceptual practice model of occupational therapy in institutional facilities, for publication and application to practice. **Method.** Interviews and focus groups with six expert occupational therapists were subjected to qualitative content analysis to confirm, disconfirm, and further develop the model. **Findings.** The model's lived-environment domain as the focus of assessment and intervention was extensively confirmed, and its quality-of-life domain as the focus of intervention goals and outcomes was both confirmed and further developed. **Implications.** As confirmed in this study, the Lived Environment Life Quality Model is a client-centred, ecologically valid, and occupation-focused guide to optimizing quality of life of institutionalized adults with dementia in present moments and progressively over time.

Abrégé

Description. Un modèle conceptuel de la pratique est requis pour expliquer les complexités écologiques associées à l'usage des occupations pour optimiser la qualité de vie des personnes atteintes d'une démence qui vivent dans des établissements de soins. **But.** Cette étude visait à préparer le Lived Environment Life Quality Model (LELQ) en vue de sa publication et de son application dans la pratique. Le LELQ est un modèle conceptuel de la pratique ayant été élaboré spécifiquement pour orienter la pratique de l'ergothérapie auprès des personnes atteintes d'une démence qui vivent dans des établissements de soins. **Méthodologie.** Des entrevues et des groupes de réflexion effectués avec six ergothérapeutes experts ont été soumis à une analyse qualitative du contenu afin de confirmer, d'infirmer et d'élaborer davantage le modèle. **Résultats.** Le domaine du milieu de vie du modèle en tant que point central de l'évaluation et de l'intervention a été confirmé dans une large mesure et le domaine de la qualité de vie en tant que point central des objectifs et des résultats de l'intervention a été confirmé et élaboré davantage. **Conséquences.** Tel que confirmé par cette étude, le modèle LELQ est un guide centré sur le client et l'occupation et écologiquement valide permettant d'intervenir auprès des adultes ayant démence et vivant dans des établissements de soins, en vue d'optimiser leur qualité de vie au moment présent et progressivement, au fil du temps.

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The Lived Environment Life Quality (LELQ) Model is a conceptual practice model developed to guide occupational therapy for people with Alzheimer's disease and related dementias whose final homes are skilled nursing, assisted living, chronic care, or other institutional facilities. Conceptual practice models emerge from unique challenges in practice, integrating theory and research that help to explain practice-based challenges and to guide professional reasoning related to them (Kielhofner, 2009). The challenge that gave rise to the LELQ Model centred on this question: How might occupational therapists best meet the occupational needs and wants of institutionalized adults with dementia in ways that optimize their quality of life (QoL), even as their dementias progress? This study aimed to prepare the LELQ Model for publication and application to practice. The problem the model addresses is introduced below with a true vignette of a man who lived his final 9 years in an assisted-living facility where he had been admitted due to progressive dementia. The need for a model of occupational therapy for institutionalized adults with dementia and influences on the LELQ Model's development are then described.

Need for and Development of the LELQ Model

> Francis was fortunate. Occupational therapists were rare in his facility, and only once did one evaluate his mobility. Yet seemingly unlike other residents, Francis benefitted from partnerships among two nursing assistants and two of his daughters, one of whom was an occupational therapist. These partnerships meant that Francis still gave expression to what mattered to him even as his dementia progressed. Hence Francis, the husband, still pointed out the mahogany chair with the cardinal on its backrest that his wife had needlepointed. He, the businessman, still counted and wrapped coins. He, the collector, still beheld his prized china birds. He, the organizer, still organized the bingo cards. He, the puzzle master, still assembled simple jigsaw puzzles. He, the joker, still joked. Additionally, Francis's apartment was arranged such that most days he still cared for himself, phoned family, wrote notes, watched TV, and played solitaire. Francis's daughters and one assistant were with him when he drew his last breath. Days before, when he had aphasia and was bedbound, he had smiled and waved at strangers. All told, one might say that Francis continued to be and to act as Francis to the very end, his dementia notwithstanding.

As Perrin and May (2000) have observed, occupational therapists are a ''rare breed'' in dementia settings, where occupation is often poorly understood (p. 1). Evidence likewise suggests that institutionalized adults with dementia are vulnerable to spending time occupationally disengaged and socially disconnected (Morgan-Brown, Ormerod, Newton, & Manley, 2011; Wood, Harris, Snider, & Patchel, 2005; Wood, Womack, & Hooper, 2009). These problems were evident in Francis's facility, where occupational therapists were rare and most residents ostensibly had little to do.

To help address these problems, we propose that a conceptual practice model is needed that explicates how the QoL of institutionalized people with dementia can be optimized, even as their respective dementias progress. To our knowledge, no such model exists. Prominent models reviewed by Kielhofner (2009) neither target dementia nor explicate unique environmental features of institutions and their implications for practice. While other dementia-specific or dementia-relevant models offer useful resources (see Allen, 1985; Gitlin & Corcoran, 2005; Perrin & May, 2000; Sifton, 2000), they were not designed to guide institution-based practice. Moreover, on the basis of findings from six systematic reviews, Padilla (2011) urged occupational therapists to focus on the environments and personal contexts of people with dementia, using occupation rather than deficit-oriented treatments. Yet it was beyond the scope of these reviews to develop a conceptual guide that operationalized these evidence-based recommendations for institution-based practice.

Development of the LELQ Model

According to Lynham (2013), development of conceptual practice models often starts with a conceptual development phase that is influenced by the theorist's direct experience with the phenomenon. The LELQ Model originated with the first author's experiences as a family caregiver (she is Francis's daughter) and as an occupational therapist for people with dementia (Wood, 2014). These experiences informed the belief that environmental support for meaningful occupation matters to people with dementia and their QoL, both in the moment and over time as dementia progresses. Thusly, rooted in practice, subsequent development of the model involved syntheses of classic works and contemporary scholarship into a guide for clinical decision making, a crucial type of translational research according to Woolf (2008).

The model's premises were first refined through research using a captive-nonhuman-primate scientific model (Wood, 2002, 2014). These studies presumed that zoos share key features of human institutions described by Goffman (1961): formally admininstered rounds of activities that structure recurring routines of daily life and occupants who are not free to leave. The model thus views residential facilities for people with dementia as homes that are institutional in nature. Influenced by Bronfenbrenner (1977) and Lawton (1989) as well, these institutional homes are viewed as ecological microsystems; that is, they are conceived to be immediate face-to-face settings of daily life with physical, social, and cultural environmental features that press toward or elicit particular QoL experiences. Environmental influences on QoL are understood to encompass built environmments and other physical features and objects (Day, Carreon, & Stump, 2000); social environments including formal caregivers (staff paid to care for residents), adminstrators, health professionals, residents, and

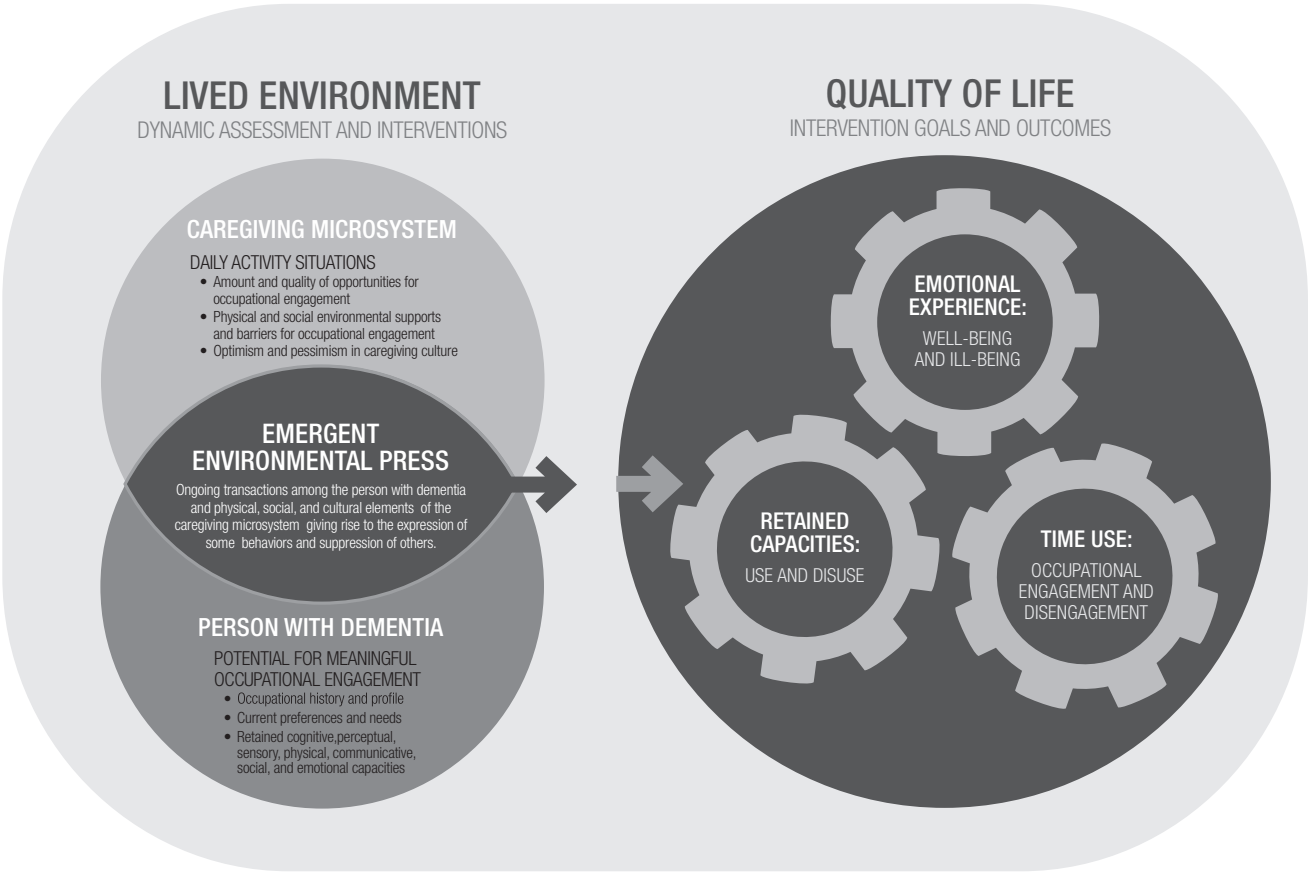

Figure 1. The Lived Environment Life Quality Model as conceptualized at the start of the study.

others (Kitwood, 1997); and institutional cultures that impact how others "see" and treat people with dementia (Wells & Dawson, 2000). Other disciplinary and interdisciplinary work influenced conceptualizations of occupation (Hasselkus, 2011) and dementia-specific QoL, encompassing considerations of time use, functioning and use of retained capacities, and emotional experiences (Brod, Stewart, & Sands, 2000; Lawton, Van Haitsma, Perkinson, & Ruckdeschel, 2000; Sloane et al., 2005). Influenced by all these works, at the start of this study the LELQ Model was conceived to have two main domains: the lived environment (focus of assessment and intervention) and QoL (focus of intervention goals and outcomes). Figure 1 depicts these domains, their relationships, and related subdomains and concepts.

If emerging models are to become credible and trustworthy guides for practice, then they must undergo critical real-world scrutiny, including systematic confirmation, disconfirmation, or refinement, or all three (Lynham, 2013). Hence, real-world scrutiny of the LELQ Model was undertaken by inviting expert occupational therapists to critically evaluate the model and its usefulness for practice. We asked this descriptive research question: In what ways do participants' evaluations of the LELQ Model and their own practice experiences and perspectives confirm, disconfirm, or further develop the model?

Method

Research Approach

A systematic approach to qualitative content analysis (QCA) as described by Schreier (2012) was used. QCA differs from many qualitative methods. Specifically, data of relevance to descriptive research questions are summarized in QCA and may be used to confirm preexisting theory. Also in QCA, coding frames are defined as ways of structuring materials that allow researchers to focus on key aspects that pertain to questions. Coding frames consist of main categories and related subcategories, which may be either concept-driven (deductively derived from prior theory) or data-driven (inductively developed from data). Furthermore, coding frames are developed early in the research process in QCA, and coefficients of agreement may be used to ensure consistency in applying frames before data are analyzed. Qualitative data analysis is characterized by interpretations of meanings embedded in data. Descriptive statistics may also be calculated in QCA to assess the coding frame's credibility, such as frequencies of code usage and percentages of selected data covered by categories and subcategories in the frame (Schreier, 2012).

We locate this study in a constructivist paradigm as described by Lincoln, Lynham, and Guba (2011). Specifically, the study is premised on these beliefs: (a) Reality is socially

co-constructed, experientially based, local and specific (ontology); (b) knowledge advances through progressively more informed and sophisticated reconstructions that coalesce around consensus (epistemology); and (c) methods are interpretive and dialogic, involving discussions and collaboration among researchers and participants (methodology).

Participants

Purposive sampling was used to find informants guided by these inclusion criteria: (a) being a licensed occupational therapist, (b) currently practicing, (c) having at least 10 years professional experience with dementia, and (d) being identified by colleagues as an expert practitioner. Six female practitioners living across the United States who met these criteria were identified through snowball sampling. Participants held two or more practice roles, including staff occupational therapist and fieldwork educator; developer of, leader of, or consultant to dementia programs; or president of a dementia-related business. Experience working with institutionalized people with dementia ranged from 10 to 29 years. The Internal Review Board of Colorado State University approved the study, and all participants signed approved consent forms.

Data Collection

Data collection involved individual interviews and focus groups. While the principal investigator (PI, WW) and three co-investigators (JL, CL, AM) were present for all data collection sessions, WW was the lead interviewer and facilitator of focus groups.

Data collection began with 60-min individual audiotaped phone interviews with each participant before she had learned about the LELQ Model. The purpose of these interviews was to gather in-depth descriptions of participants' practice experiences and perspectives that were unbiased by prior knowledge of the model. In response to open-ended questions, participants described their current and past work, shared an especially satisfying and a dissatisfying practice story, and offered a clinical "pearl," or what was most important in practice.

Six focus groups were next conducted in three stages to evaluate the LELQ Model. Each participant contributed to one focus group at each stage. All focus groups used online meetings to enable real-time dialogue among participants and were 90 min and audiotaped. In Groups 1 and 2 (Stage 1), participants were introduced to the LELQ Model as illustrated in Figure 1 and shared first impressions of it. In-depth evaluations of the model's main domains and their theorized interrelationships, subdomains, and concepts occurred in Groups 3 and 4 (Stage 2). These evaluations continued in Groups 5 and 6 (Stage 3), along with discussions of the model's congruence with participants' practices and recommended clarifications or changes.

Data collection concluded with individual 60-min audiotaped phone interviews. These interviews sought to verify each participant's evaluations of the LELQ Model.

Investigators described the research process at the start of all data collection sessions and encouraged participants to share their honest appraisals of the model. Data were also collected and analyzed iteratively, allowing ongoing member checking of emerging findings during focus groups and final interviews.

Data Analysis

Audiotaped interviews and focus groups were transcribed verbatim and uploaded into the qualitative software program NVivo (Edhlund, 2012) for analysis. The study's coding frame was developed and consistency in its application was achieved prior to the start of formal data analysis. WW and the co-investigators developed the preliminary coding frame, applied it to data from initial interviews, and met weekly over 4 months to review and progressively refine the frame. After multiple revisions and eventual consensus indicating that the coding frame was nearing finalization, NVivo's coding comparison function was used to eliminate repetitive codes and resolve remaining discrepancies in code definitions and applications. With these corrections, the coding frame was finalized. Kappa coefficients were then calculated to assess consistency in applying this frame across investigators. Computed Kappa coefficients were .75 or higher, suggesting high consistency.

The final coding frame encompassed eight main categories that were exhaustive and mutually exclusive. Six concept-driven categories were derived from the respective subdomains of the lived environment and QoL domains illustrated in Figure 1: caregiving microsystem, person with dementia, environmental press, time use, retained capacities, and emotional well-being. A seventh concept-driven category addressed long-term perspectives on QoL. Data-driven subcategories were developed and associated with each of these seven categories. For example, under *person with dementia*, developed subcategories included assessments, occupational history, preferences and needs, and relationships among others. An eighth category, critical appraisals, was developed to capture explicit and direct appraisals of the model; associated subcategories were recommendations, confirmations, and disconfirmations. The disconfirmations subcategory was developed to capture any indicators for which participants viewed the model (or elements of it) as flawed, unworkable, or not useful for practice.

Transcribed texts from the six initial interviews and six focus groups were qualitatively coded on a line-by-line basis using this final coding frame. More exactly, researchers used the seven concept-driven categories and their subcategories as codes to tag segments of texts from this database that they interpreted as supporting or otherwise aligning with the model's domains, concepts, or theorized relationships. Texts coded with these seven categories and related subcategories thus demonstrated unambiguous compatibility with the model. For example, in her clinical pearl offered before having learned about the model, one participant stated that "learning the

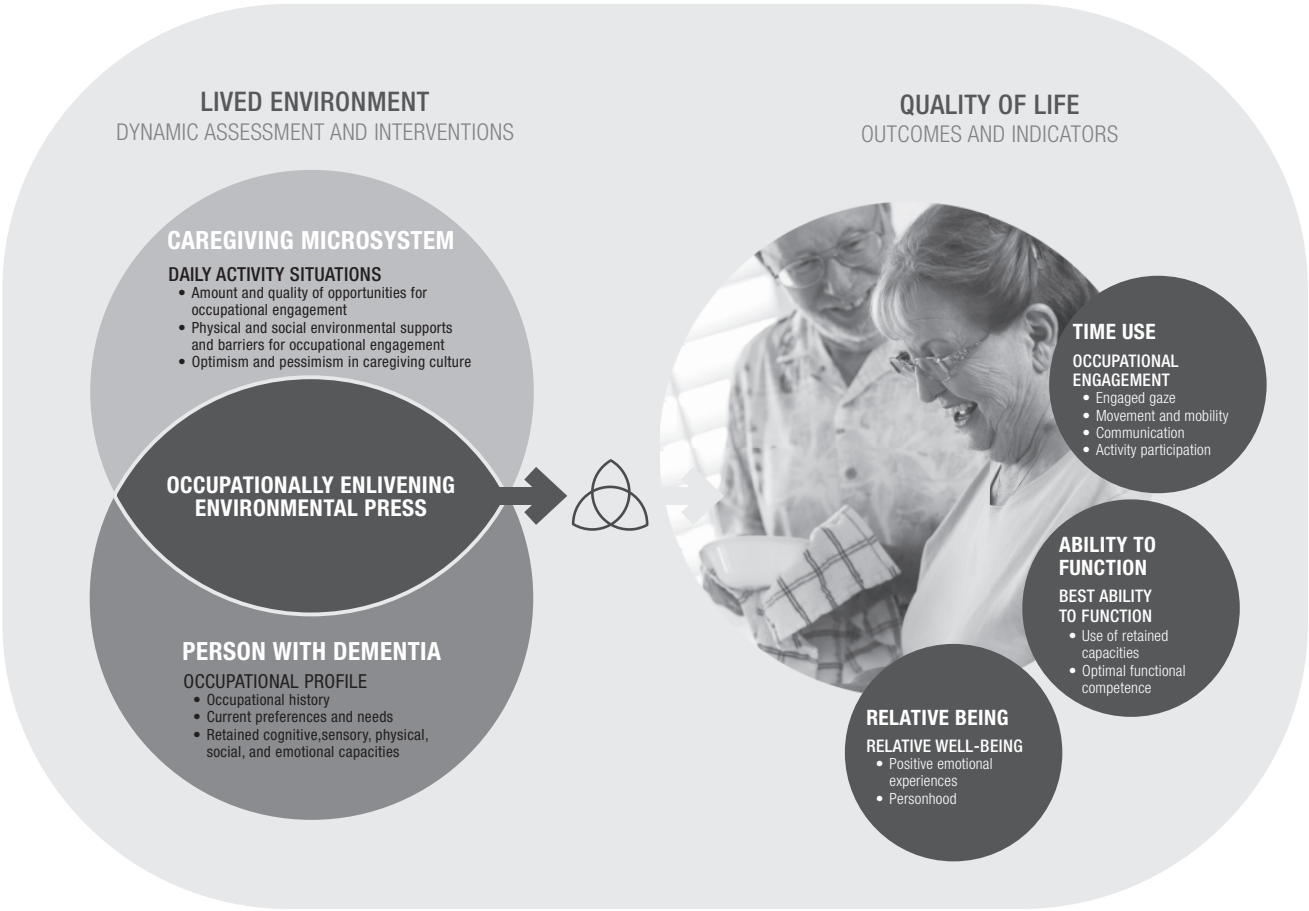

Figure 2. The Lived Environment Life Quality Model: Occupationally enlivening environmental press in the present moment.

person's occupational history [and] interests" was most important in practice. These comments were interpreted as strongly aligned with the model's approach to people with dementia and coded "person with dementia, occupational history." During a focus group when the model's concept of environmental press was under review, another participant stated she agreed with the concept "1000%." This explicit affirmation was coded "critical appraisal, confirmation."

After qualitative coding of initial interviews and focus groups was completed, frequencies of code usage and percentages of all coded texts covered by the frame's eight categories and subcategories were computed to quantify the degree to which the model was confirmed or disconfirmed. Final interviews were examined to ensure accurate understandings of participants' critical evaluations of the model as it had been further refined throughout the study.

Trustworthiness

These strategies recommended by Elo et al. (2014) and Schreier (2012) for enhancing the trustworthiness of QCA were followed: (a) Inclusion criteria helped ensure that participants had relevant expertise; (b) data collection was directly linked to a descriptive research question; (c) the coding frame was tested, modified, and finalized, and consistency in its application was obtained prior to data analysis; (d) multiple researchers analyzed data to enhance comprehensive and soundness of interpretations; and (e) researchers regularly reviewed analyses and resolved discrepancies. Additionally, related to presentation of findings below, (f) all participants' perspectives were represented, (g) findings were summarized and illustrated with figures, and (h) confirmation of the model was quantified with descriptive statistics while the model was brought alive through qualitative analyses that linked its key concepts with participants' actual practice experiences, clinical insights, and convictions.

Findings

Ninety-three percent of all data from initial interviews and focus groups was interpreted as confirming the LELQ Model. Texts interpreted as confirming the lived-environment domain were coded 1197 times, covering 69% of this database. Texts interpreted as confirming the QoL domain were coded 421 times, covering 24% of this database. Participants' critical appraisals were coded 113 times, covering the remaining 7% of the database; these

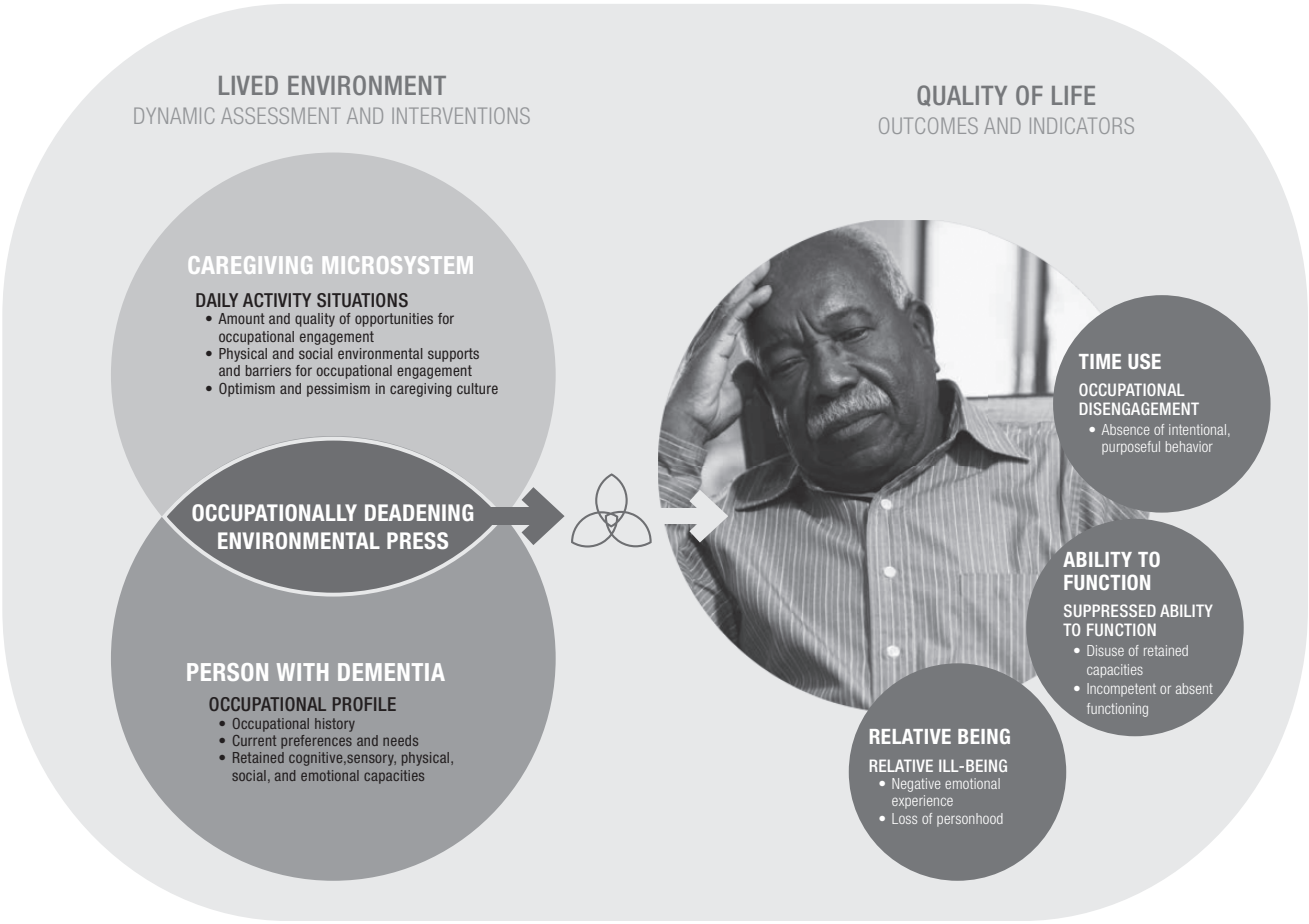

Figure 3. The Lived Environment Life Quality Model: Occupationally deadening environmental press in the present moment.

coded texts either explicitly confirmed the LELQ Model or further developed and clarified its QoL domains. No texts were interpreted as disconfirming.

Figures 2 and 3 depict the model as now supported by findings. In Figure 2, an occupationally enlivening environmental press is indicated by much overlap of the lived-environment subdomains of the caregiving microsystem and person with dementia. The arrow from the environmental-press subdomain points to a small Venn diagram that also has much overlap among its elements; these elements symbolize the three QoL subdomains of time use, ability to function, and relative being. An occupationally enlivening press is thus shown to support the woman's simultaneous occupational engagement, more optimal ability to function, and relative well-being: observable indicators of positive QoL experiences. Figure 3 illustrates an occupationally deadening environmental press, inducing the man's occupational disengagement, suppressed ability to function, and relative ill-being: observable indicators of negative QoL experiences. Thus as comparisons of Figures 2 and 3 with Figure 1 suggest, the research process fully confirmed the lived-environment domain, and both confirmed and further developed the QoL domain. Other findings that further elucidate the model are presented next.

The LELQ Model: Lived-Environment Domain

As the focus of assessment and intervention, the lived-environment domain embodies three subdomains: caregiving microsystem, person with dementia, and environmental press. Code frequencies and percentages of covered data for these subdomains were 642 (37%), caregiving microsystem; 223 (13%), person with dementia; and 332 (19%), environmental press.

Caregiving microsystem. In the model, *caregiving microsystems* refers to face-to-face settings of institutional homes for adults with dementia. Attention is foregrounded to daily activity situations that serve to organize and structure the passage of time. Activity situations involve routine times for self-care, meals, television, activity groups, and downtimes (periods without structured activities), among other activities. In an explicit confirmation, one participant shared that the concept of activity situations captured how she worked "with individuals to optimize their meaningful engagement" and with caregivers to help them "understand how activity situations can be molded to best suit the individual rather than the institution." She initiated these thoughts by exclaiming, "I really love the categorization of activity situations!"

The model also highlights opportunities for occupational engagement availed by activity situations, including social and physical environmental supports and barriers to engagement. Participants strongly confirmed these emphases. Regarding physical environmental interventions, participants described diverse efforts in their practices aimed at minimizing distractions, removing hazards, maximizing homelike qualities, and setting up activities to support participation in private and public activity areas. Several participants had also played leadership roles in designing or redesigning the built environments of dementia facilities. Regarding social environmental interventions, participants described extensive collaborations with formal caregivers plus involved family and friends. As one participant said, caregivers need to learn how to provide opportunities for "meaningful occupation throughout the day so there can be many opportunities at different times." Toward these ends, several participants reported contributing to employee training programs.

Participants also confirmed the model's focus on cultural pessimism and optimism and how cultural assumptions permeate daily activity situations. The model poses that cultural pessimism is suggested when caregivers mainly view institutionalized adults with dementia through a lens of dementia and disability. Before introduced to the model, for example, one participant described the caregiving culture of Mary's nursing home as "pessimistic." Mary's daughter had asked this participant for a consultation after being told by staff that "Mary was close to death." During her consultation visit, the participant found Mary in a downtime, "hunched over withdrawn and alone." She also spoke with Mary's formal caregivers, who repeated, "Mary can't do anything anymore. She has dementia. She's dying." The participant then watched the caregivers comb Mary's hair and sit her in a corner.

The model poses that cultural optimism is suggested when caregivers view institutionalized adults with dementia mainly through a lens of possibility for meaningful action and human connection. Confirming this concept, several participants described their efforts to make caregiving cultures more optimistic by getting "buy-in" facilitywide. One participant, who noted that "culture change is hard and slow," persisted until she "finally got the whole facility on board." Another participant described "a chameleon" approach to buy-in. With administrators or owners, this participant stressed "paying points, like revenue, census, or risk mitigation." With nurses, she stressed "quality outcomes." With caregivers, she modeled activity-based approaches that eased their jobs while helping people with dementia be more engaged. Altogether, participants viewed cultural assumptions as having the power both to uplift and "environmentally suppress" the abilities and well-being of people with dementia.

Person with dementia. The lived-environment subdomain *person with dementia* focuses on occupational profiles as guides to intervention. One participant's clinical pearl confirmed this focus when she asserted that "learning the person's occupational history, occupational interests, and function—who that person is, has been, what they've long enjoyed doing" was most important in practice. Participants furthermore concurred that getting to know people with dementia as occupational beings was "really the first place to start." They thus persistently asked questions, such as What are peoples' interests, habits, routines, or favorite foods? What do they do for fun? What were their past occupations? Who are their family or friends?

Indeed, participants reported going out of their way to gather occupational profiles. For example, one participant told of Ella, a new nursing home resident who had started "zoning out," increasingly staring at her lap in growing isolation. "It was a sad thing," the participant said, "because we couldn't get hold of any family and I really wanted to know what she was all about, just to touch some familiarity within her." One day while in her office, the participant saw someone visiting Ella in the dining room. She bolted out to ask the visitor to tell her "all about" Ella. The visitor shared, "She had such an impact on my life. She was the choir director for 35 years. She taught me so much about music." When asked to "belt out one of those hymns that Ella taught you," the visitor started singing. Ella's head rose from her lap "for the first time" and she began singing too. "This was the beginning," the participant observed, "of finally understanding something about Ella."

Participants also described using informal observations coupled with formal assessments to ascertain retained capacities in relationship to occupational histories and preferences. The participant who had visited Mary reported learning from Mary's daughter that Mary once was a secretary and loved opera. After putting Mary in front of a typewriter and asking her to type her name, Mary "sat up real straight" and moved her fingers across the keys. These simple acts marked the beginning of discovering "more and more about Mary's preferences and cognitive abilities." This participant used Allen's (1985) cognitive levels to assess Mary's cognitive capacities. After ascertaining Mary's occupational history, connecting it to her capacities, and observing her usual care, the participant concluded that Mary's abilities were being "environmentally suppressed" and no medical reason existed for her to be dying.

Environmental press. The LELQ Model foregrounds attention to person–environment transactions in the context of daily activity situations. Every moment, these transactions are theorized to press people with dementia to act, be, and feel in particular ways, thereby eliciting particular QoL experiences. Environmental presses are posed to exist on a continuum from occupationally enlivening to occupationally deadening. Occupationally enlivening environmental presses are most likely in optimistic caregiving cultures wherein formal caregivers and others "see" and help to realize a person's potential for occupational engagement, and the physical environment likewise supports engagement. Occupationally deadening environmental presses are most likely when social, physical, and

cultural environmental elements interact such that a person's capacities and will to act are largely unsupported.

Participants strongly confirmed these concepts. One participant shared that the concept of environmental press "was really important in the model" because it offered "a really important role for OT [occupational therapy]." Another participant declared, "I am very happy to see that term! I think it makes so much sense as an OT [occupational therapist] and how we can predict and impact patterns of behaviour." Moreover, many experiences described by participants suggested intuitive grasps of prevailing environmental presses and compelling desires to transform deadening presses into enlivening ones. For example, one participant's first observations of Claudia were of Claudia sitting passively mute in the dining room, "eyes shut, falling half out of her chair while aides fed her giant spoonfuls of pureed food, yelling at her to swallow." Finding this situation intolerable, the participant trialed games, textures, and objects to learn what Claudia "liked to touch and manipulate" and what got her attention and challenged her balance. Within 3 weeks, Claudia began staying alert during meals and was sufficiently balanced and interested in food that she was feeding herself. Returning to Mary, the participant's initial visit led her to recommend that Mary move to another facility. In this new facility, Mary's therapists discovered that she liked gambling and invited her to use the facility's slot machine for a fun way to improve her physical capacities.

Participants additionally reported using established occupational therapy methods in activity situations to help people experience occupationally enlivening presses. Among others, these methods involved analyzing, grading, and adapting tasks to ensure just-right challenges; providing meaningful activities that motivated engagement; and tailoring activities to peoples' interests and capacities. After learning what worked, participants shared their knowledge with others. In Ella's case, for instance, the participant collaborated with Ella's friend, who, as her "co-treater and co-partner," helped Ella do familiar things that mattered to Ella. The participant also changed Ella's daily routine so she could attend musical activities in her facility.

The LELQ Model: QoL Domain

As the focus of intervention goals and outcomes, the QoL domain embodies three subdomains, each of which is understood to be strongly environmentally influenced: time use, ability to function, and relative being. The subdomain *time use* refers to how people with dementia actually occupy time in daily activity situations, or their relative occupational engagement versus disengagement. The subdomain *ability to function* addresses the quality of people's functioning as calibrated to their dementia severity. The subdomain *relative being* encompasses emotional experiences and personhood. Owing to participants' suggestions, personhood came to be defined as a unique sense of self that is conducive to positive experiences, including feelings of confidence and competence. As illustrated in Figures 2 and 3, the model poses that occupationally enlivening environmental presses elicit positive QoL experiences and occupationally deadening presses elicit negative QoL experiences.

Participants agreed that goals and outcomes for institutionalized adults with dementia necessarily require attention to co-occurrences of QoL indicators across all three subdomains. They viewed the QoL subdomains as indivisible wholes, that is, as simultaneously involving some level of occupational engagement, functional competence, and relative well-being. As one participant observed, "It's symbiotic." You give a person "an opportunity to do something and they can do it. They feel a sense of competence and have confidence to try a harder level of that activity or generalize that feeling of confidence to the next activity." Several participants noted that agitated behaviours also illustrate why simultaneity of QoL indicators across subdomains was important to heed. For instance, while spending time pacing or rummaging suggests some occupational engagement and competence, QoL may still be compromised by the anxiety or boredom driving these behaviours. To better illustrate this indivisibility of QoL indicators, the gears in Figure 1 were replaced with the small-centred Venn diagrams in Figures 2 and 3.

The proposition about indivisibility was further upheld when considering the progressive nature of dementia and people in advanced stages. One participant reported knowing many people who, owing to sustained environmental support, "were mobile longer, had more coherent and enjoyable conversations and better nourishment longer, laughed and smiled more, and [had] healthier engagement with family and friends." "From the standpoint of mortality," she concluded, "those who are occupationally engaged live longer than those who are not." Indeed, participants concurred that if institutionalized adults with dementia predominantly experience occupationally enlivening activity situations over time, then they are less prone to depression, malnutrition, dehydration, pressure sores, or falls, among other adverse conditions. Mary, for instance, once viewed as near death, was still singing opera and participating in self-care when last seen 3 years after moving to her new facility. Participants likewise concurred that QoL could often improve even in end stages of dementia. As one participant expressed, "The person is never really locked out." "There are always glimmers of ways to engage," even if 20-second eye contacts, 5-second smiles, or responses to music and touch that "create that moment of connection, that moment of joy."

Discussion

It was presumed in this study that if the LELQ Model was credible and trustworthy, then participants' critical evaluations plus practice experiences and perspectives would confirm the model's theorized concepts and premises and also further clarify and develop them. This presumption was upheld. Implications of findings are further developed below as a guide to occupational therapy for institutionalized adults with dementia.

Implications for Practice

Client-centred practice. As "really the first place to start," the lived-environment domain of the LELQ Model guides occupational therapists to assemble occupational profiles of institutionalized persons with dementia directly from them plus formal caregivers and knowledgeable others. Given evidence that some cognitive, physical, social, and emotional capacities persist in end stages of dementia (Wells & Dawson, 2000), the model directs practitioners to assess people's retained capacities and also interpret these capacities in light of their occupational histories and current preferences and needs. As suggested by our findings, therefore, if occupational therapists were guided by the model, then they might trial adapted or graded activities that align with people's occupational histories or current preferences and needs in activity situations that are more or less deadening as presently constituted yet essential, for instance, times for meals, dressing, or bathing. Through this trailing and other information gathering, occupational therapists would ascertain what environmental supports help people spend time in activity situations in ways that simultaneously support their willful occupational engagement on some level, put their existing capacities to use, and are emotionally acceptable if not also interesting or satisfying.

By foregrounding a person's potential for meaningful and healthful occupational engagement regardless of dementia severity, the model embodies Yerxa's (1998) belief that occupational therapists are "search engines for human potential" (p. 413). Occupational therapists are, in other words, uniquely qualified to "discover a person's resources and emphasize what the person can or might be able to do instead of a person's incapacities; what's right instead of what's wrong" (Yerxa, 1998, p. 413). The model similarly promotes key elements of client-centred practice enumerated by Sumsion and Law (2006). Namely, the model promotes practices in which occupational therapists seek to know people with dementia as occupational beings. It promotes hopeful practices, which legitimately presume that better rather than worse QoL is possible more often than not. It promotes partnerships among occupational therapists, people with dementia, and others who do or can influence their QoL. Moreover, by arming occupational therapists with knowledge of people's occupational profiles, the model well positions them to advocate on behalf of and empower exceptionally vulnerable individuals.

Ecologically valid practice. The lived-environment domain of the LELQ Model emphasizes physical, social, and cultural environmental interventions that create and sustain occupationally enlivening presses within daily activity situations. Descriptions of practices reported by this study's participants suggest what these environmental interventions might entail.

Related to social and cultural environmental elements, for example, if guided by the LELQ Model, then much work of occupational therapists would involve identifying activity situations with occupationally deadening environmental presses and partnering with others to transform those presses into sustainably occupationally enlivening presses. To do so, occupational therapists would observe daily activity situations to gain insights into prevailing cultures and related caregiving practices of institutional homes. They would collaborate with formal caregivers and others to find alternatives to "parking" institutionalized people with dementia in deadening activity situations for purposes of surveillance, control, and safety, as often occurs (Egan, Hobson, & Fearing, 2006; Wood et al., 2005, 2009). They would model how challenging activities can be handled in ways that make caregivers' jobs easier and more satisfying while also helping people with dementia be more satisfactorily and competently engaged. They would seek to obtain buy-in to an occupational perspective on dementia facilitywide, perhaps by leading training programs that provide reasons for optimism even in end stages of dementia. Related to physical environmental elements, occupational therapists would focus on minimizing physical barriers and maximizing physical supports to occupational engagement in public and private activity areas. Occupational therapists could, as well, help to redesign, or design anew, built environments of institutional homes from an occupational perspective.

Because assessment and intervention approaches guided by the LELQ Model would transpire within or directly address daily activity situations in which institutionalized people with dementia spend considerable time every day, they would be ecologically valid. Indeed, the model constitutes an ecological conceptual practice model as described by Brown (2014) precisely because it assumes that occupational therapists ought to emphasize environmental support. Pullout practices in institutional facilities, or practices in which practitioners remove people from their everyday environs to treat them in segregated therapy spaces using methods that emphasize deficit reduction, would therefore be rare. (For parallels to inclusive versus pullout school-based practice, see Spencer, Turkett, Vaughan, & Koenig, 2006.)

Occupation and QoL in the now and over time. Informed by this study's findings plus other research (Egan et al., 2006; Hasselkus, 2011; Wood, 2014; Wood et al., 2005, 2009), the LELQ Model's conceptualization of dementia-specific QoL centres on occupation. Spending time predominantly occupationally disengaged undermines functioning, a vital dementia-specific element of QoL (Sloane et al., 2005). Over time, such disengagement also invites considerable excess disability, or functional incapacity not directly attributable to neurodegenerative dementias themselves (Rogers et al., 2000). Environmental support for occupational engagement—even if only listening to favorite music, holding recognizable objects, or intentionally focusing on interesting others or happenings—is thus highly preferable to cultural acceptance of pervasive disengagement as normative in dementia.

The model accordingly theorizes two interrelated temporal perspectives on dementia-specific QoL: QoL in the present moment and the progression of QoL over time. First, the model

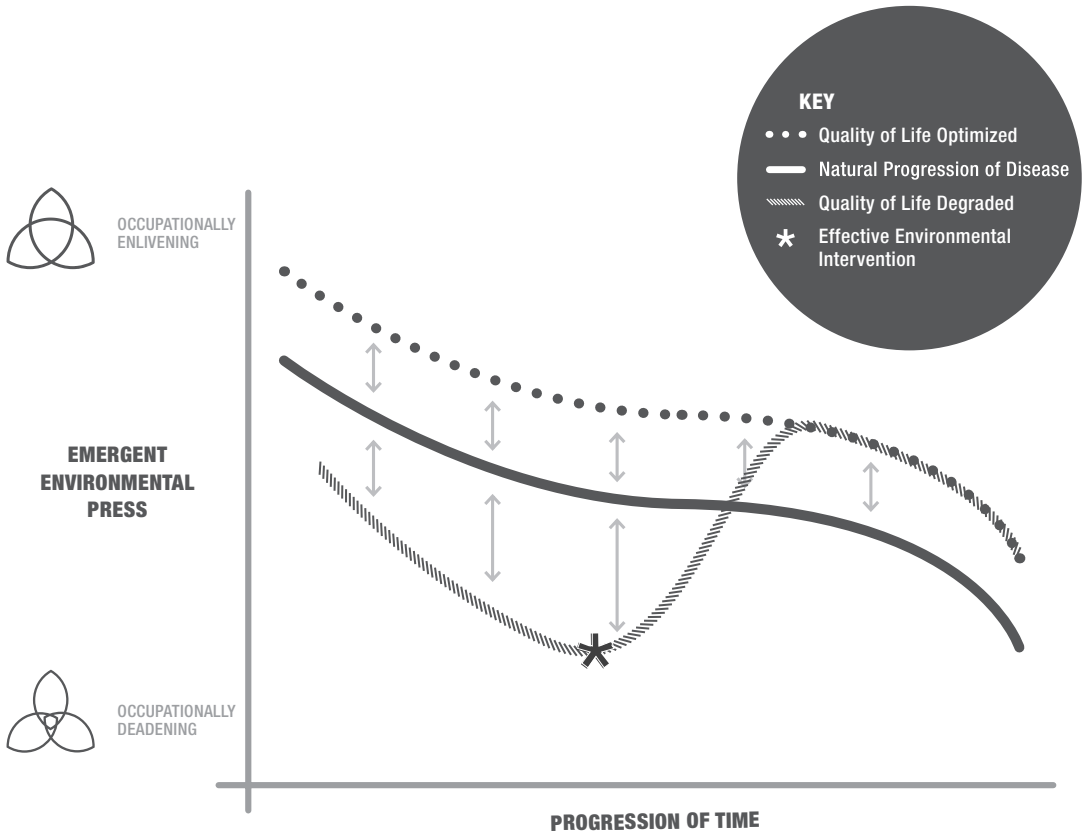

Figure 4. The Lived Environment Life Quality Model: Progression of quality of life over time.

poses that transactions among caregiving microsystems and people with dementia give rise to emerging environmental presses and associated QoL experiences fairly simultaneously in the immediate now. Second, the model poses that these moment-by-moment experiences have a progressively multiplicative impact on QoL over time (see Figure 4). Namely, QoL is optimized over time when people with dementia routinely experience daily activity situations with occupationally enlivening environmental presses. A better rather than worse QoL is therefore possible even as dementias neurologically progress. The model thus both recognizes natural disease progressions and poses that environmental interventions may meaningfully reverse or slow degrading trajectories that are attributable to excess disability. Supporting this supposition are the stories of Mary, Ella, and Claudia in this study, which offered examples of reversals of functional loss through social support, or ''rementia'' as termed by Kitwood (1997).

Ultimately, practice guided by the LELQ Model would be client centred, ecologically valid, and also occupation focused as defined by Fisher (2014). The concept of occupation is integral to the model's emphasis on occupational profiles, its delineation of the occupational nature of environmental presses, and its conception of dementia-specific QoL. The model is therefore congruent with Padilla's (2011) evidence-based recommendations that occupational therapists focus on the environments and personal contexts of people with dementia, using occupation rather than restorative treatments. It can additionally guide professional reasoning to help implement these recommendations in institutional settings.

Because reliance on institutional care is increasing, the LELQ Model is also timely. In 2006 in Canada, ''approximately half of all individuals with dementia'' resided in institutions (Egan et al., 2006, p. 139). The World Health Organization and Alzheimer's Disease International (2012) have projected that by 2050, 115.4 million people will have dementia worldwide. Changing demographics globablly will also result in fewer family caregivers, further increasing reliance on institutional care in the coming decades.

Limitations

Several practices specific to QCA were used to enhance the study's trustworthiness and thereby help readers reach their own conclusions about the credibility, authenticity, and usefulness of findings. It cannot be assumed, however, that occupational therapists beyond this study's participants would similarly confirm the LELQ Model, perhaps especially less experienced practitioners or practitioners from countries with different health care systems than in the United States or differing cultural views of dementia. In addition, while this study subjected the LELQ Model to critical real-world scrutiny, it did not apply the model.

Future Research

Next research steps will need to emphasize the application phase of theory building (Lynham, 2013). In particular, development of a process model is needed to guide implementation of the model in real-world settings. Feasibility and acceptability of the model in real-world settings must also be ascertained. Pilot testing of the model's theoretical suppositions, especially as related to progression of QoL over time, is also needed.

Conclusion

The LELQ Model was confirmed and further developed in this study as a useful and trustworthy guide for client-centred, ecologically valid, and occupation-focused services aimed at optimizing the QoL of institutionalized adults with dementia. We propose that the model may help occupational therapists infuse institutional homes with hopeful occupational perspectives that uplift the QoL of people with dementia in their everyday experiences and over time as their dementia progresses. We also invite further critical scrutiny of the LELQ Model's theoretical premises and impact of its real-world applications.

Key Messages

- The Lived Environment Life Quality (LELQ) Model is a conceptual practice model that was developed to guide occupational therapy for institutionalized people with dementia.
- The LELQ Model prioritizes client-centred, ecologically valid, and occupation-focused approaches to assessment and intervention in order to optimize dementia-specific indicators of quality of life in present moments and progressively over time.
- The LELQ Model may help to situate occupational therapists as indispensable practitioners and leaders in dementia-care programs within residential institutions.

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