Creating compassionate spaces for end-of-life care: Protocol for an environmental assessment of hospice settings for older people experiencing homelessness

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Abstract

Background: With current data supporting an increasing population of OPEH requiring end-of-life (EOL) care, understanding the environmental factors that influence their wellbeing is crucial.

Methods: The Aging in the Right Place (AIRP) study aims to address this gap by developing and implementing the Aging in the Right Place – Hospice Environmental Assessment Protocol (AIRP-HEAP) and AIRP-HEAP Secondary Observation (SO) tools. The AIRP-HEAP tool evaluates the built and natural environment within hospice settings. Adaptations were made to ensure alignment with the unique needs of OPEH, such as reconceptualizing spiritual care and expanding the definition of family accommodation. Additionally, the AIRP-HEAP SO tool supplements this by capturing contextual data on the surrounding neighbourhood of the hospice site, providing a holistic understanding.

Results: The anticipated results will highlight the importance of considering environmental factors in hospice environments and inform recommendations to improve EOL care for OPEH.

Conclusion: Data collected using these audit tools can guide environmental modifications in hospice settings to facilitate aging and EOL care in the right place. Thus, this protocol paper aims to promote the adoption of best practices in hospice design to better support this vulnerable population.

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Keywords: hospice, end-of-life, homelessness, older adults, protocol

Abstract

Purpose: This protocol paper provides a comprehensive overview for evaluating hospice environments tailored to the needs of older people experiencing homelessness (OPEH). **Background**: With current data supporting an increasing population of OPEH requiring end-of-life (EOL) care, understanding the environmental factors that influence their wellbeing is crucial. **Methods**: The Aging in the Right Place (AIRP) study aims to address this gap by developing and implementing the *Aging in the Right Place – Hospice Environmental Assessment Protocol (AIRP-HEAP)* and *AIRP-HEAP Secondary Observation (SO)* tools. The AIRP-HEAP tool evaluates the built and natural environment within hospice settings. Adaptations were made to ensure alignment with the unique needs of OPEH, such as reconceptualizing spiritual care and expanding the definition of family accommodation. Additionally, the AIRP-HEAP SO tool supplements this by capturing contextual data on the surrounding neighbourhood of the hospice site, providing a holistic understanding. **Results**: The anticipated results will highlight the importance of considering environmental factors in hospice environments and inform recommendations to improve EOL care for OPEH. **Conclusion**: Data collected using these audit tools can guide environmental modifications in hospice settings to facilitate aging and EOL care in the right place. Thus, this protocol paper aims to promote the adoption of best practices in hospice design to better support this vulnerable population.

Background

Having a place to call home is a fundamental necessity required to fulfill an individual's needs for safety, security, and mental wellbeing. However, not everyone has the privilege of having these needs met. According to a Point-in-Time (PiT) survey – which provides a glimpse into the minimum number of people experiencing homelessness in a 24-hour period – 4,821 people were experiencing homelessness in Vancouver. This number marks a stark 32% increase from the PiT

conducted in 2020 [1]. The proportion of older people experiencing homelessness (OPEH) has also risen, comprising 22% of the homeless population [2]. OPEH face rising demands for medical services, home care, and end-of-life care [3]. Evidence reveals that the homeless population in Vancouver experiences higher rates of premature death [4], cancer [5], and chronic illnesses [6] compared to the housed population. Moreover, individuals experiencing homelessness often require access to healthcare services 10-20 years earlier than the housed population due to frailty and age-related conditions [7].

The concept of "*end-of-life (EOL) care in the right place*" emphasizes the importance of providing appropriate housing that aligns with individuals' unique needs and lifestyles as they approach the end of their life journey. This concept holds important implications for OPEH, a demographic characterized by multifaceted health trajectories. Within the Canadian landscape of EOL care, hospice care plays an integral role. Hospice care is a philosophy of care that offers medical, social, and emotional support, which can be provided at home or within a care facility [8]. This philosophy contributes to the notion of EOL care in the right place, as hospice care's holistic approach allows individuals' unique needs to be met. Given that the homeless population in Canada is both growing and aging, it places greater and unique demands on EOL care services [6]. Unfortunately, this vulnerable population also faces exclusion from these very services due to a lack of continuity and interruptions to care [9], discrimination [10], shortages of hospice accommodation [11], and limited specialized palliative care services [12].

The spatial understanding of hospices fits with the historical development of the concept, dating back to physical buildings which provide care to sick and dying individuals [13]. Understanding hospices as physical facilities for EOL care allows us to examine how their physical make-up either facilitates or inhibits effective care for individuals at the end of life. This understanding is crucial for enhancing our knowledge of how the built environment influences EOL care in the right place. For OPEH, the built environment of hospice facilities is especially significant,

as research underscores the critical role that space plays in their access to end-of-life care [9,11]. Environmental audits (also referred to as environmental observations or assessments) are useful in evaluating the built environment and can identify ways to improve the environment and placemaking characteristics in different types of housing, including hospice settings. [Author blinded for review] and colleagues [10] reported findings from an environmental audit of a temporary housing program for OPEH, which highlighted the integral role of spatial and placemaking aspects to aging in the right place. In the present study, we extend this previous research by applying a therapeutic goals lens [14] to evaluate the extent to which spatial and placemaking factors (e.g., spatial configuration, design and layout, connections to nature, access, and scope of personalization) can promote comfort, privacy, sociability, control, dignity, and spiritual expression in hospice setting to understand whether these settings are appropriate for aging and EOL care in the right place for OPEH. To examine the built environment of the hospice care (Maggie's Lodge), we developed an Aging in the Right Place - Hospice Environmental Assessment Protocol (AIRP-HEAP) tool.

Study Objective

EOL in the right place is an extension of the Aging in the Right Place (AIRP) project, which emphasizes the significance of secure and optimal housing that assists an individual's unique vulnerabilities [12]. The concept of AIRP acknowledges that what constitutes the 'right' place for an older adult to age in will vary from person to person [15]. (Author blinded for review) [10] devised an AIRP conceptual framework drawing on insights from experts in aging, homelessness, and housing services as well as older adults with lived experience of homelessness. AIRP project's conceptual framework comprises of six subcategories which are indicators for AIRP for OPEH. These subcategories are: 1) built environment of the housing unit and surrounding neighborhoods, 2) offsite and onsite health and social services and resources, 3) social integration, 4) stability and affordability of space, 5) emotional place attachment, and 6) broader political and economic context. This protocol paper's focus is on the built environment audit, thus the first indicator of the

conceptual framework, which is the built environment of the housing unit and surrounding neighborhoods. An unsupportive built environment can have damaging effects on the quality of life of OPEH. Given that this paper is based on the development of an environment audit tool, the built environment identifies notable features of the building such as amenity rooms, green spaces, security cameras, etc. [10]. The AIRP project documents and evaluates “promising practices” of shelter/housing that support aging in the right place for OPEH. Promising practices are understood as inventive models that have not gone through rigorous evaluation but hold the promise of supporting AIRP for OPEH [14]. One such promising practice for the Vancouver site of the AIRP project is Maggie’s Lodge that provides EOL care to OPEH in Vancouver [14].

Methods/Design

Audit Tool Development

The Aging in the Right Place – Hospice Environmental Assessment Protocol (AIRP-HEAP) tool is an adapted version of the Hospice Environmental Assessment Protocol (HEAP) tool developed by [Author blinded for review] [16]. The original HEAP tool was developed as a standardized method for evaluating whether the spatial and placemaking characteristics of hospice buildings support eleven therapeutic goals: 1) continuity of self, 2) access to nature, 3) privacy, 4) social interaction, 5) safety and security, 6) autonomy, 7) stimulation and sensory therapies, 8) spiritual care, 9) family accommodation, 10) support after death, and 11) support for staff [16] (see Table 1 for definitions of each goal). Each goal includes several design objectives and sub-objectives that operationalize the respective goal, and each objective includes specific environmental items that are observable within the hospice environment, totaling 295 items. For example, the therapeutic goal of ‘continuity of self’ has two design objectives: ‘creating a non-institutional environment or home-like environment’ and ‘scope for personalization’ which each have specific environmental items. The ‘scope for personalization’ objective includes ‘wall shelves present to display personal belongings’ and ‘adequate space in individual rooms is provided to bring personal belongings.’ We adapted these

11 therapeutic goals for the AIRP-HEAP tool to be conceptually linked to domains within the AIRP conceptual framework [10]. The AIRP conceptual framework was developed to provide a practical conceptualization of 6 indicators that contribute to AIRP for OPEH, and the AIRP-HEAP tool domain was based on this framework [10]. Based on this framework, the AIRP-HEAP tool domains are: 1) built and natural environment, 2) housing access and home modification, 3) emotional place attachment, 4) social support/participation/inclusion, and 5) safety and security. The synergy between the AIRP framework's concepts and the therapeutic goals of the AIRP-HEAP tool helps to ground the environmental characteristics of hospice sites within the conceptual discussion of aging and EOL care in the right place (overlap of these are also shown in Table 2).

Audit Tool Revision

The AIRP-HEAP audit tool is designed to collect data on the presence or absence of environmental features with options: "Yes," "No," or "N/A." According to [Author blinded for review] [16], when a majority of these items are present in a hospice setting, it suggests that the therapeutic goals are being achieved. For this study, [Author blinded for review]'s original HEAP tool [16] was revised to better align with the needs of AIRP study participants, as the original tool was initially designed to evaluate hospice sites for the general population. With input from relevant stakeholders, we made several adaptations to [Author blinded for review]'s [16] tool to include considerations for the unique needs of OPEH in hospice. For example, the goal 'spiritual care' was reconceptualized as 'culturally appropriate/relevant/supportive spiritual care' to align with the needs of the Indigenous population, who are overrepresented in homeless counts in Metro Vancouver [1] and elsewhere in Canada [17]. In addition, the definition of 'family accommodation' was expanded from 'family members' to 'loved ones' to represent the diverse support networks of OPEH who receive care and support from friends and close non-kin loved ones [18]. To adopt a less biomedical approach, we replaced 'patient' and 'nurse' with 'staff', 'individuals', and 'people'. Furthermore, we added an open-ended comment section for each goal to allow auditors to provide detailed notes for

additional context as needed.

While the AIRP-HEAP tool captures data about the indoor space of hospice sites, a separate complementary tool, the AIRP-HEAP Secondary Observation (SO) tool, is used to capture contextual data on the neighborhood surrounding the hospice site. The AIRP-HEAP SO was adapted from the qualitative observation section of the Stakeholders Walkability/Wheelability Audit in Neighborhoods (SWAN) tool [19], which is a user-led audit tool that evaluates the environmental barriers to walkability and wheelability of neighborhoods for diverse older adults and persons with disabilities. The AIRP-HEAP SO tool consists of six open-ended questions about land use, area characteristics, quality of public space and amenities, feelings of safety, travelling on foot or wheeling, and overall traffic volume, speed, and noise.

Data Collection

Two research assistants will independently audit the hospice sites using the AIRP-HEAP and AIRP-HEAP SO tool. The audit data will be subsequently exported and organized into an Excel file separated by hospice site for analysis. The raw data will be checked to identify blank entries. If blank entries are identified, they will be discussed with the research assistant who conducted the audit to identify the reason and will be subsequently addressed. Given that two research assistants will independently audit each site, raters' answers will be compared to determine if each response are the same ("=TRUE") or different ("=FALSE"). The discrepancies will be identified and discussed to understand the reason behind the differences which will then be resolved by consensus. The final data used for analysis will be a consensus of answers between both research assistants. The "N/A" responses will be omitted from scoring due to their lack of applicability. For instance, if the primary question (e.g., room present to accommodate family and loved ones) is answered "No," then the sub-questions (e.g., about the size of that room) would be considered not applicable ("N/A"). Qualitative data collected with the AIRP-ENV SO tool will be imported into NVivo 12 [20] for analysis.

Data Analysis

After a consensus is reached on the presence/absence ratings for each item (‘Yes’, ‘No’), the data will be converted into quantitative scores (‘Yes’=1; ‘No’=0). Quantitative data will be summed and a total score (%) for each sub-objective will be calculated. A 5-item Likert scale will be created to rate each design objective and follow a scoring system where 0% to 20% = “Unusually poor,” 21% to 40% = “Poor,” 41% to 60% = “Moderate,” 61% to 80% = “Strong,” and 81% to 100% = “Exceptional.” An overall goal score will not be calculated as each goal has differing design objectives and sub-objectives, thus having inequivalent denominators, which would result in unbalanced interpretation of the data. Therefore, scoring and interpretation will be performed based on the design objective(s) within each therapeutic goal. Using NVivo 12, the qualitative AIRP-HEAP SO data will be coded line-by-line and subsequently collated to form conceptual categories. This will initiate the development of a codebook for the AIRP-HEAP SO data that will be reviewed and approved by fellow research team members.

Significance Score vs. Total Score

Within the AIRP-HEAP tool, certain items were noted as “significant” design objectives based on [Author blinded for review]’s [16] original HEAP tool. The significance of items was determined through consensus by experts and normative standards. To further confirm the significance of these items for aging and EOL care in the right place for OPEH, we performed an in-depth review of relevant literature. If these significant items were not present at the audit sites, their absence will be analyzed with more scrutiny as these are seen as crucial in spatial and placemaking aspects linked to AIRP for OPEH. In these cases, we will consider the possible reasons for why these significant items may have been missing. In Table 3, the values under “Significant Score” will factor in the weight of these significant scores (as a percentage), while the values under “Total Score” will consider all items without accounting for significance (as a percentage). “Significant Score” will be calculated by dividing the number of significant objectives that are marked present at the hospice site by the total number of significant objectives as labelled in the HEAP tool. This score will allow us to

focus only on those characteristics of the hospice that have broader implications (for example, are mandatory) for aging and EOC care in the right place for OPEH. “Total Score” will be calculated by dividing the number of objectives that are marked present at the hospice site by the total number of objectives, including the significant objectives. This score will allow us to calculate the overall rating of the hospice site based on the Likert scale, and comparison between hospice sites will mainly be based on this score. Comparing the “Significant Score” and “Total Score” provides a comprehensive assessment of the quality of the built environment at the hospice sites.

Ethics

The protocol for AIRP under the title “Aging in the Right Place: Building Capacity for Promising Practices that Support Older People Experiencing Homelessness in Montreal, Calgary, and Vancouver” was approved by the Kuali Protocol System at Simon Fraser University (approval number 20200204), McGill University, (20-09-008), and the University of Calgary (REB20-1229) Ethics boards. All study sites provided informed consent.

Results

The results based on the findings will contribute to the understanding of the significance and influence of environmental factors in EOL care of hospice residents. This tool was used to collect data at Maggie’s Lodge from November – December 2024. The data analysis and write up of the findings is estimated for May 2025.

Discussion

This protocol aims to provide a comprehensive methodology for conducting a study focused on assessing hospice settings for OPEH in Metro Vancouver. Through this study, new insights into the environmental aspects that influence OPEH's ability to age and receive EOL care in suitable settings will be gained, ultimately contributing to the well-being of this population. Thus, this study allows us to discover information regarding AIRP concepts related to HEAP goals for end-of-life care and identify the environmental facilitators and barriers to improvements in hospice settings in

the neighborhoods.

For capturing data and information on this protocol, the AIRP-HEAP tool (for indoor space) includes 295 items categorized into 11 therapeutic goals pertaining to the built and natural environment of hospice sites and the AIRP-HEAP secondary observation (SO) tool (for surrounding neighborhoods) will be used. The most detailed questions in the AIRP- HEAP tool domains are related to the inside of the building will be asked through a questionnaire in order to evaluate the quality of EOL care space. These tools will be used to assess the indoor built environment and outdoor environment surrounding Maggie's Lodge Hospice in Metro Vancouver area. This is a six-bed hospice with a home-like setting and 24-hour nursing care that provides integrated, trauma-informed EOL care for structurally vulnerable populations. Built environment factors that enhance safety, reduce stress, and have spiritual significance will be audited to evaluate the quality of the built environment. For instance, assessing the amount of natural light in the building, ensuring security and privacy measures, providing spiritual and counseling spaces, and creating areas that facilitate social communication are included in the audit tool. Additionally, elements like accessible and wheelable sidewalks, traffic calming features, sufficient outdoor spaces, support services, and social amenities in the surrounding environment are included in the secondary observation tool as these factors are known to promote potential for social and outdoor engagement for OPEH and their loved ones.

To ensure that the solutions recognized through this protocol can be extended to other hospice centers, we will develop a set recommendation based on the findings. These recommendations will outline the best practices and actionable steps for improving the built environment and surrounding neighborhoods of hospice settings catering to OPEH. Additionally, we will share the results of the study, along with the developed guidelines, with relevant stakeholders, including policymakers, urban planners, architects, and healthcare providers. By disseminating this information widely and encouraging its implementation in other hospice centers, we can promote the adoption of similar

improvements across different locations, thereby extending the benefits to a broader population of OPEH.

Limitation

This study will be conducted exclusively at Maggie's Lodge hospice during a specific time frame to evaluate the quality of its built environment and surroundings of the building. While the findings based on the audit tool are expected to contribute to addressing gaps in literature, the study will be subject to several limitations. Firstly, as the audit will take place at a single point in time, the data will not capture environmental changes that occur over time. Future studies will be able to examine temporal factors and weather impacts on outdoor spaces of hospices over time. Additionally, while the AIRP-HEAP tool will offer valuable insights into hospice environments, its adaptation from an existing tool may overlook certain unique needs of OPEH. Finally, the study's focus on Maggie's Lodge hospice site in Metro Vancouver will limit the generalizability of the findings to a broader geographical and cultural context.

Conclusion

The development of the AIRP-HEAP and AIRP-HEAP SO audit tools add diversity and detail to existing hospice environment assessment methods by incorporating the unique needs of OPEH. The findings from these tools will help identify spatial design and placemaking features within hospice environments that either promote or deter EOL care for this population. By aligning the AIRP-HEAP goals to AIRP-related concepts, this research is expected to strengthen the connection between design-related therapeutic goals and research-based conceptualizations of aging and EOL care in the appropriate setting. The anticipated findings of the audit are expected to provide guidance for identifying environmental improvements in hospice settings, as well as inform future planning and design guidelines for hospice settings that support OPEH.

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Table 1. Eleven Therapeutic Goals of the HEAP tool

Therapeutic Goals	Definition
Provide continuity of self	Environmental characteristics that help preserve or support patients' past activities, preferences, and awareness
Provide access to nature	Environmental characteristics that provide opportunities for visual and physical access to nature
Provide privacy	Environmental characteristics that facilitate patients' choices in various levels of privacy through regulation of visual and auditory stimuli
Facilitate social interaction	Environmental characteristics that facilitate and enable meaningful interaction between patients with staff, their family, and other patients
Maximize safety and security	Environmental characteristics that maximize safety and security of patients, staff, and families
Provide autonomy	Environmental characteristics that enable patients to exercise choice and personal preference about their environment and everyday life
Regulate stimulation and support sensory therapies	Environmental characteristics that contribute to an appropriate quantity and quality of sensory experience, and support sensory therapies (palliative therapies)
Provide spiritual care	Environmental characteristics that facilitate opportunities for patients' spiritual care; religious, philosophical, and existential or personal beliefs, values, practices, and preferences
Provide family accommodation	Environmental characteristics that facilitate patients' family accommodation and support control, functional independence, comfort, privacy, recreation, and spiritual care
Provide support after death	Environmental characteristics that support care and dignity for patients and their families during the moment of death, body removal, bereavement, and remembrance
Maximize support for staff	Environmental characteristics that support staff (care providers) for better communication, observation, efficiency, satisfaction, and wellbeing

Table 2. Link Between AIRP Conceptual Indicators and AIRP-HEAP Tool Therapeutic Goals

AIRP Conceptual Indicators	Therapeutic Goals of AIRP-HEAP Tool
Built and natural environment	1. Provision of access to outside view/nature 2. Regulate stimulation and support sensory therapies
Housing access and home modification	3. Continuity of self 4. Culturally appropriate/relevant/supportive spiritual care
Emotional place attachment	5. Provision of privacy 6. Provision of autonomy
Social support/participation/inclusion	7. Facilitate social interaction 8. Accommodation for loved ones 9. Support after death 10. Maximize support for staff
Safety and Security	11. Maximizing safety and security

Table 3. Example of Design Scores Across Eleven Therapeutic Goals

	Score		Rating	
	Significant	Total	Significant	Total
Goal 1: Continuity of Self				
Objective 1: Non-institutional environment or home-like environment				
Objective 2: Scope for personalization				
Goal 2: Provision of Access to Outside View/Nature				
Objective 1: Maximize daylight, views, and fresh air through design				
Goal 3: Provision of Privacy				
Objective 1: Provides privacy in individual rooms				
Objective 2: Privacy concerns in social spaces, circulation spaces, and in outdoor areas are attended to				
Goal 4: Facilitate Social Interaction				
Objective 1: Opportunities in individual rooms				
Objective 2: Opportunities to interact in social or common spaces				
Objective 3: Opportunities in outdoor social spaces				
Goal 5: Maximize Safety and Security				
Objective 1: Mitigation of potential hazards				
Objective 2: Provides support and preparedness for infection control				
Objective 3: Provides support for security from theft and vandalism				
Goal 6: Provision of Autonomy				
Objective 1: Control over microenvironment and physical settings				
Objective 2: Control over daily routine and activities				
Goal 7: Regulate Stimulation and Support Sensory Therapies				
Objective 1: Provides or enhances positive therapeutic stimuli through environmental design				
Objective 2: Regulates levels of acoustic, visual, and olfactory stimulation				
Objective 3: Provides support for therapies				
Goal 8: Culturally Appropriate/Relevant/Supportive Spiritual Care				
Objective 1: Facilitates support of spiritual care and cultural practices				
Objective 2: Provides facilities for spiritual care and cultural sensitivities in formal spaces, informal spaces, and in individual rooms				
Goal 9: Accommodation for Loved Ones				
Objective 1: Easy accessibility and wayfinding				
Objective 2: Provides comfortable accommodation for loved ones to stay for a few days or for a short visit				
Goal 10: Support After Death				
Objective 1: Provides support during the moment of death				
Objective 2: Provides support for deceased individual's body removal or transfer from the building				
Objective 3: Provides support after death and departure of deceased individual				
Goal 11: Maximize Support for Staff				
Objective 1: Provides privacy and comfort for staff				
Objective 2: Provides support for socialization, relaxation, and recreation				
Objective 3: Provides support to ease in observation and care				

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