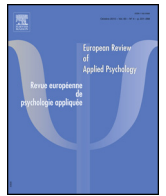




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Original article

Perceptions on well-being at home of families with people with disabilities: A psycho-environmental perspective



Chez-soi et bien-être perçu par des familles dont un membre à une incapacité physique : une perspective psycho-environnementale

D. Labbé^{a,b,*}, S. Jutras^{a,b}, S. Coulombe^{a,b}

^a Département de psychologie, université du Québec à Montréal, C.P. 8888, succursale Centre-ville, Montréal, Québec, Canada

^b Centre de recherche interdisciplinaire en réadaptation, Montréal, Québec, Canada

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ABSTRACT

Introduction. – Although the home is of major importance in the lives of people with disabilities, few studies address disability in the literature on home and health. Moreover, people with disabilities and their family members' perceptions of their homes has rarely been explored.

Objective(s)/Method. – Using the psycho-environmental potential model as an analytic framework, we conducted interviews with 31 people with spinal cord injury (SCI) and their families. The interviews addressed their perceptions of how their dwellings were promoting or hampering their well-being.

Results. – Findings showed that the home was perceived by respondents as beneficial to their well-being for a variety of reasons that covered a spectrum of psychological and social needs. Disability seemed to affect the experiences of people with SCI and their family members in different ways.

Conclusion. – This study illustrates the importance of considering home and disability in a way that goes beyond physical adaptations and includes the various needs of all household members to promote optimal well-being.

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RÉSUMÉ

Introduction. – Le chez-soi est particulièrement important dans la vie des personnes ayant des incapacités ; pourtant, dans la littérature sur le chez-soi et la santé, peu d'études portent sur l'incapacité. Peu de chercheurs se sont intéressés aux perceptions qu'ont les personnes ayant des incapacités et les membres de leur ménage sur leur chez-soi dans leur vie quotidienne.

Objectifs/Méthode. – Inspirés par le modèle du potentiel psycho-environnemental, nous avons conduit des entrevues avec 31 familles vivant avec une personne ayant une lésion médullaire (LM). Les entrevues concernaient leurs perceptions sur la façon dont la maison contribuait ou nuisait à leur bien-être dans le chez-soi.

Résultats. – Les résultats ont montré que la maison soutenait le bien-être dans le chez-soi de diverses façons, associées à une variété de besoins psychologiques et sociaux. L'incapacité semble teinter différemment l'expérience du chez-soi des personnes avec une LM et celle de leur proche.

Conclusion. – Cette étude montre l'importance de traiter de la relation « chez-soi et incapacité » sans se limiter aux adaptations physiques pour considérer les besoins variés de chacun et ainsi contribuer au bien-être.

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Mots clés :

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* Corresponding author at: Département de psychologie, université du Québec à Montréal, C.P. 8888, succursale Centre-ville, Montréal, Québec H3C 3P8, Canada.
 E-mail address: delphinelabbe80@gmail.com (D. Labbé).

Introduction

According to the [World Health Organisation \(1986\)](#), individuals must be able to realize their aspirations, satisfy their needs, and evolve within their environment to attain high levels of physical, mental, and social well-being. Thus, one's well-being requires access to a number of conditions and resources, such as adequate housing ([World Health Organisation, 1986](#)).

The person-environment interaction, central in the social model of disability, is described as the result of the transaction between environmental factors, a person's health condition, needs, and preferences ([WHO, 2001](#)). Physical impairments lead to transformations in people's capacity, which, in turn, modifies both their relationship with their house and the people living with them ([Heywood, 2004](#)). Often their dwelling requires modification to fit the household's new needs ([Aplin, de Jonge, & Gustafsson, 2015](#); [Driedger, Crooks, & Bennett, 2004](#)). For people with disabilities, having access to adequate housing is an important environmental factor and is central to allowing them to carry out their activities and fulfill their social roles ([Fougeyrollas, Bergeron, Cloutier, Côté, & St-Michel, 1998](#)). Thus, it is important to better understand how the house contributes to, or hampers, the well-being of people with disabilities and other members of their household. In this study, well-being is defined as a positive state in which people perceive that their needs are met in all aspects that matter to them, such as emotional life, control, sense of coherence and social relations ([Jutras, 2006](#)).

Researchers distinguish between the "home" (i.e. the emotional, behavioural and social experiences that happen within the home) and the "house" (the physical structure). The home is generally recognized as a complex, multi-faceted ([Coolen & Meesters, 2012](#)), and universal experience ([Smith, 1994](#)). The home can be both a positive and a negative experience for people with or without disabilities ([Aplin et al., 2015](#); [Heywood, 2005](#); [Mallett, 2004](#)). Researchers of different disciplines, such as architecture, history, anthropology, phenomenology, and psychology, have studied the role of the home for non-disabled people, each having a different focus (for an extensive review, see [Després, 1991](#); [Moore, 2000](#) or [Coolen & Meesters, 2012](#)). In environmental psychology, studies on the meaning of home have focused on the qualities and the inhabitants' perceptions of what supports or hinders well-being in the home. In early studies, both empirical and theoretical, inventories of meanings or qualities of the home were often compiled in a decontextualized manner, without any relation to the actual dwelling of the inhabitants ([Moore, 2000](#)). To address this criticism, subsequent studies took a more contextualized approach by examining the concrete experience and use of the home (e.g. [Aragones, 2002](#); [Cloutier-Fisher & Harvey, 2009](#); [Gale & Park, 2010](#)). This contextualized approach helped improve our understanding of the association of the physical environment of the house and perceptions of well-being at home.

The house, in its entirety, has been the centre of interest of most of researchers studying the home (e.g. [Cloutier-Fisher & Harvey, 2009](#); [de Jonge, Jones, Phillips, & Chung, 2011](#)). However, [Coolen \(2006\)](#) suggested that focusing on how specific features of the house are perceived by the inhabitants would be more pertinent, since dwellings are heterogeneous, and people usually do not perceive them as a unique entity but rather distinguish their various features. In the literature on non-disabled people, few studies have examined the contribution of specific features of the house (e.g. windows in [Kaplan, 2001](#)) or the association between specific features and well-being at home (e.g. how housing characteristics support family well-being in [Miller & Maxwell, 2003](#)). To the best of our knowledge, only [Meesters \(2009\)](#) has considered the perceptions associated with each house's sub-setting. With the exception of house modifications, research on how specific features of the

house contribute to or hamper well-being at home has never been examined among people with disabilities. As disabilities may transform the individuals' experience of specific rooms, it is important to understand better their distinctive contributions to well-being at home.

Although the home is of major importance in the lives of people with disabilities, disability is scarcely addressed in the literature on home and health ([Heywood, 2004](#); [Oldman & Beresford, 2000](#)). There is a gap in the literature with respect to how home is perceived by people living with disabilities and their family members in their everyday lives. Studies on private housing mainly focused on the impact of housing modifications on the inhabitants (e.g. [Aplin et al., 2015](#); [Tanner, Tilse, & de Jonge, 2008](#)). For instance, studies showed the positive impact of housing modification on the use of skills and the sense of security of people with disabilities ([Aplin et al., 2015](#); [Pettersson, Lilja, Hammel, & Kottorp, 2008](#)).

Moreover, the studies that do exist on home and disabilities mostly focus on older people or children with disabilities, neglecting disabled adults who likely perceive their environment from a different perspective ([Kaiser & Führer, 1996](#)). Research also concentrates on home services and community housing ([Oldman & Beresford, 2000](#)), which ignores the large population of Canadians with disabilities, aged 15 years and older, living in private housing (over three million in 2012) ([Arim, 2015](#)). To our knowledge, only [Gibson et al. \(2012\)](#) have studied well-being at home among disabled adults living in private housing. They suggested that an appropriate home contributes to physical and psychological well-being, commitment to work, and participation in social and civic life for people with disabilities.

Finally, existing studies on the home and disability largely focus on people with disabilities, ignoring their families ([Heywood, 2004](#)). In Canada, more than 70% of adults with disabilities live in private housing with other household members ([Dubé, 2013](#)). The few studies that did include family members mainly examined the impact of the home on caregiving tasks ([Oldman & Beresford, 2000](#)). To our knowledge, no study on home and disability has focused on the daily experience of household members and their well-being at home.

Psycho-environmental potential model

This study used the *psycho-environmental potential model* (as named by [Jutras, 2002](#)) to better understand how the house and its characteristics contribute to, or hamper, the well-being at home of people with disabilities and those living with them. It was developed by [Steele \(1973\)](#) to assess a physical setting, which comprises multifarious components, including:

- the physical features itself (e.g. structure, air, furniture);
- the feature's properties, such as air temperature or furniture layout;
- the impact on the user's experience ([Steele, 1973](#)).

The model assumes that a setting should sustain six functions: shelter and security, social contact, symbolic identification, task instrumentality, pleasure, and growth. According to this model, there is no 'good' or 'bad' setting. Instead, the users evaluate if a setting sustains or limits a function ([Steele, 1973](#)). The model focuses on the interaction of the user with the environment and on how the user's needs fit with the setting characteristics. The psycho-environmental potential model has been previously applied to different environments (doctors' office, [Jutras, 1983](#); classrooms, [Culp, 2006](#); a library, [Kenreich, 2001](#); and a community centre, [Breton, 1984](#)). In this study, the model was used to investigate perceptions of how the house contributes to, or hampers,

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