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Creating "therapeutic landscapes" at home: The experiences of families of children with autism

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ABSTRACT

This study explores the challenges faced within the home environment by North American families of children with autism. The study also examines the diversity and extent of physical modifications introduced by the families to alleviate these challenges. The concept of therapeutic landscapes is employed as a framework to examine how physical modifications transform the home environment into a place of healing for both the children with autism and their family members. Finally, the study offers a general design framework that can ultimately guide home designers and policymakers in developing friendly home environments for children with autism and their families.

1. Introduction

Autism spectrum disorder (ASD) has increasingly become an everyday reality for many North American families. A recent study (Baio, 2012) showed that autism now affects one in every 88 children and one in every 54 boys in the United States. Every hour, three children in the United States are diagnosed with autism. Whether these numbers signify better detection, broadening diagnostic criteria, or increased incidence is debatable. However, what is unquestionable is that autism is now considered a notable part of our developmental landscape (Liu et al., 2010).

Autism is a life-long developmental disability that typically manifests during the first three years of life, affecting how individuals perceive their environment and interact with others. It is often characterized by impairments in social interaction, verbal and non-verbal communication skills, imagination, and sensory processing, apart from repetitive patterns of behaviors, interests, and activities. Problematic behavior frequently associated with autism includes aggression, self-injury, destruction to property, and tantrums. These behaviors deteriorate the quality of life not only for the individual with autism but also for the members of their family (Koegel et al., 1996).

A growing body of evidence suggests that behavioral problems are linked to the sensory environment in which the behavior is displayed (Carr, 2007). Sensory dysfunction in children with autism causes them to perceive the world differently—they may be either hyper- or hyposensitive to the stimuli present in their daily environment (Kern et al., 2007). As a compensation mechanism, they respond to the lack of or abundance of sensory input with specific abnormal behavioral signs and symptoms commonly associated with autism (Albano, 2008). Reports suggest that modifying or adjusting the sensory input in their environment may promote more positive behavior (Anderson, 1998). Thus, given the potential impact of the physical environment on the functional and social performance, perception, behavior and, ultimately, the quality of life of individuals with autism, it is essential to tailor the built environment to accommodate their specific needs. Robertson (2010) argues that living in a society designed for non-autistic people contributes to, and aggravates, many of the daily life challenges that autistic individuals experience. Hence, rethinking the design of our everyday spaces is an urgent need.

Smith et al. (2012) estimate that 60% of newly built single-family units in the United States will house at least one person with a disability over the expected lifetime of the unit. This is possibly one of the many reasons that home modification has received considerable attention in the fields of occupational therapy, nursing, environmental psychology, architecture, interior design, and health geography. As the primary contextual setting, the home has powerful physical, psychological, emotional, and spiritual significance in our lives, and it is considered to provide "the optimal, essential environment for healing" (Marshall, 2008, p. 263). The home can also operate as a place of struggle, and perceived as a life-defying force, as Williams (2002) suggests when critically examining the idealized notion of home for family caregivers providing 'family-focused care' at home.

Home modifications involve changes or alterations to the physical features of the house to reduce demands on the physical environment and ensure convenient, safe, and independent living (Fange and Iwarsson, 2005; Pynoos, 1993). Some scholars have expanded the

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definition of physical modification to include installation of special equipment, and other aspects that family caregivers deem important (Messecar et al., 2002). A significant body of research has discussed home modifications and their roles in improving the quality of life of elderly (Hong et al., 2015; McDowell, 2013), and people with a wide range of physical and mental impairments (Allen et al., 2017; Bowes et al., 2017; Guillet et al., 2017; Ahmad et al., 2013; Bhidayasiri et al., 2015), as well as their caregivers and family members (Jutras et al., 2015; Davy et al., 2014).

Despite the growing interest in modifying the physical environment to suit autism needs, most of the available literature focuses mainly on educational spaces (Martin, 2016; McAllister and Sloan, 2016; Khare & Mullick 2009), treatment centers (Pomana, 2014) or new residential spaces for adults with autism (Beaver 2010). Research on the diversity and extent of physical interventions to the home space and their impacts on the quality of life of children with autism and their families remains surprisingly underdeveloped (Owen and McCann, 2017; Evans et al., 2003; Pengelly et al., 2009). Tukiman et al. (2015) and Mostafa (2014) discussed home modifications related mainly to the sensory needs of children with autism. However, they focused only on the impacts on the child with autism, overlooking its effects on other family members. Owen and McCann (2017) addressed the experiences of families and highlighted the need for micro-scale modifications to foster the sense of containment through the creation of boundaries and 'space within space'. However, these studies used a case study approach, where between 2 or 7 cases were utilized, raising concerns about the generalizability of the findings (Noor, 2008). Also, the studies were based in settings outside of North America (Australia, Malaysia, and Egypt), thereby underscoring the need for a broader investigation of home modifications and their impacts on the quality of life of North American children with autism and their families.

In 1991, Gesler proposed the therapeutic landscapes theory, a conceptual framework for analyzing how the physical, social, and symbolic environments—broadly termed landscapes—contribute to healing and wellbeing (Gesler, 1992, 2003). Since its emergence, the theory has been actively employed to better understand the dynamics between places and wellness (Williams, 1999). These include exploring the attributes that contribute to the therapeutic nature of a: beach (Collins and Kearns, 2007); spa (Gesler, 2003), or; national park (Palka, 1999), through to considering the linkages between health and spaces within everyday geographies, such as: the home (Coyle, 2004; Donovan and Williams, 2007; English et al., 2008; Williams, 2002); community gardens (Milligan et al., 2004), and; zoos (Hallman, 2007). The therapeutic landscape theory has also been employed in the study of settings for special populations and marginalized groups, such as alcoholics (DeVerteuil et al., 2007); support group users (Davidson and Parr, 2007); the homeless (Bridgman 1999), and; people with mental disabilities (Geores and Gesler, 1999). It has also been extensively used to explore the therapeutic properties of healthcare sites and services, including hospitals (Gesler and Curtis, 2007; Crooks and Evans, 2007) and assisted living residences (Cutchin, 2007).

While therapeutic landscapes can be designed to promote physical, mental, and spiritual wellbeing, the landscape alone does not produce a therapeutic effect—it is an individual's characteristics and interactions with the socio-environmental setting that produce a therapeutic outcome (Dunkley, 2009). To incorporate the individuality of such encounters, Conradson (2005, p. 339) proposed the phrase "therapeutic landscape experience." He describes such an experience as a "positive physiological and psychological outcome deriving from a person's imbrications with a particular socio-natural-material setting." Similarly, Duff (2011) discussed the term "enabling places," which capture "a particular quality of experience - an accretion of feelings, capacities, opportunities and interaction" (Duff, 2011:149). Such enabling qualities encourage opportunities for physical activity, recreation, and social interaction, in addition to moderating stress and anxiety. He explains that the material characteristics of places can enable potential social relationships, effective responses, and wellbeing.

As a holistic concept, therapeutic landscape theory presents an ideal framework to explore the role of physical modifications in transforming the home environment into an enabling space of healing for autistic children and their families. The therapeutic value of home modifications has been discussed in the context of family caregivers providing palliative care (Donovan and Williams, 2007), and breast cancer survivors seeking psychological healing (English et al., 2008). However, the concept is yet to be applied to analyzing the effects of home environment and modifications in the context of autism.

This study contributes to the limited literature on autism-related home modifications. Relying on the experiences of North American families with autistic children, the study explores their everyday challenges in the home space, as well as the wide spectrum of physical modifications introduced by them to alleviate these challenges. It also contributes to the therapeutic landscapes literature by examining the role of physical home modifications in transforming the home environment into a place of healing for both the children with autism and their family members. Further, the study discusses how the findings can inform home design and building codes aimed at developing autism-friendly settings, thus improving the quality of life of the growing autistic population as well as their families. The next section describes the process of data collection and analysis. This is followed by the presentation of the results and, subsequently, a discussion of the potential implications of the main findings of the study.

2. Methods

Data were collected via an online questionnaire targeted at North American families with children with autism. Online surveys rely on the internet's ability to reach a large number of families with a wide range of perspectives, challenges, and experiences. In the questionnaire, which consisted of both quantitative and qualitative questions. Families were asked to share their: demographic characteristics; their housing profile; the prevalence of autism-related sensory sensitivities among their children; the autism-related challenging behaviors displayed by their children in the home environment, and; the psychological, social, and physical challenges faced as a result of having a child with autism at home. Families were also asked about the physical modifications introduced in the home environment to alleviate these challenges and improve their quality of life, in addition to the cost and the source of funding for the modifications. Participants were encouraged to describe their daily experience before and after modifying their home environment, and report whether they were satisfied with the results. The aim of the survey was not to achieve a set of statistically significant results, but rather to gain insight into the experiences of the families concerned.

After receiving research ethics approval from McMaster University, the questionnaire was posted on Survey Monkey, a commercial survey-hosting tool. Information about the online survey was shared with autism organization networks in Canada, such as Autism Ontario, Autism Speaks, and Autism Canada. Further, it was distributed to autism treatment centers and autism support groups across Canada and the United States. The targeted sample included families of children with autism who met the following inclusion criteria: one child with autism (3–16 years), at least one sibling, and had lived in the same home for at least one year. Using snowball sampling, participants were encouraged to tell others (who fulfilled the inclusion criteria) about the study. The total number of respondents recruited over a two month period was 168. One of the limitations of the study is that it included only the perspectives of the parents and not the other family members living in the home. As will be discussed, descriptive statistics were used to examine the results of the entire survey sample. Data from the qualitative questions were analyzed using thematic content analysis.

3. Findings

The surveyed families (n = 168) contributed 472 statements