

Theory and practice: the response of people with neurodegenerative disorders to home design in Western Australia

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Abstract— People with neurodegenerative disorders (NDD) who live in and want to remain in the community often have to modify their home or move to a different home to accommodate their changing needs. This paper examines one aspect of the home environment as experienced by people with NDD, in terms of Lawton's [1] model of environmental gerontology, using data from a 2007 postal survey in Western Australia. The paper concludes that, for people with declining mobility, house design is clearly an important factor involved in enabling people with NDD, and indeed frail people in general, to manage their physical difficulties and remain in their homes.

I. INTRODUCTION

IN the housing construction industry there are a number of guide documents which recognize that, for the physically vulnerable, living conditions at home can improve if the house can be designed, or readily modified, to increase safety, functionality and comfort. Two such guide documents are Australia's adaptable housing design standard [2] and 'WoonKeur', a user-quality label for housing in the Netherlands that indicates barrier-free architectural design, supportive interior design, and technologically-advanced assistive devices [3]. In this paper these types of guide documents are referred to as inclusive design documents.

In Western Australia, inclusive design documents tend not to be used as mandatory reference points for either the building of new homes or the modification of existing homes [4]. Whilst inclusive design may not be an issue for able-bodied residents, it can be a serious issue for people who are frail, disabled or infirm, including people with neurodegenerative disorders (NDD).

Most people who are diagnosed with a NDD, such as Multiple Sclerosis (MS), Motor Neurone Disease (MND), Parkinson's Disease (PD) and Huntington's Disease (HD), want to remain in their own home as their disorder progresses. However, for many of these people, their existing housing fails to respond to their changing needs when their mobility and ability to undertake activities of daily living (ADLs) (see [5] for a detailed explanation of this metric) are compromised. As the speed and pattern of deterioration from NDD for any individual is unknown, the adequacy of current housing is a perpetual concern for all parties involved including the individuals themselves, their

families (many of whom provide informal care), the health and allied health professionals who treat them and the agencies that support them in their homes.

This paper examines one section of data from a 2007 postal survey in Western Australia covering the home support needs of people with NDD living in the community. The data considered is related to difficulties with ADLs due to declining mobility and resultant home modifications and/or moves to a different house. Lawton's [1] model of environmental gerontology is used as a framework for the discussion and an extension of this model is tested using the data.

II. BACKGROUND

Inclusive design is a concept of social inclusion to counter the limitations posed on numerous end-users by the general principle of designing for the 'average' end-user [6]. Inclusive design can have an impact not only on the well-being of the individual, but also on the range of possibilities for care in the home by home care providers, on the demand for institutional care and on the wider housing market.

People with NDD can be disadvantaged in their home environment as the onset of these disorders is frequently unexpected. Symptoms of NDD include compromises in both mental and physical function. Physically, patients can exhibit partial to complete incontinence, tremor, poor balance, muscle rigidity, and/or muscle weakness or paralysis. Some people with NDD have difficulty retaining their independence either due to their physical infirmity or a particular design aspect of their living environment. However, no studies of the home support needs of people with NDD specifically refer to inclusive design as a means of improving the housing experience of these people. Nor are there housing studies that look specifically at the fit between people with NDD and their home living environments.

As there are some similarities between the mobility and functioning of frail aged individuals and people with NDD, it is useful to look at some of the many studies that consider housing design issues for older people ([4], [7] - [9]). Of these studies, Karol [4] specifically looked at the housing market for new and renovated homes in Western Australia. She found that neither the supply nor the demand side of this market were considering inclusive design features. It is not suggested that inclusive design is a panacea that will enable all people with NDD to remain at home throughout the course of their disorder. Rather, the design of the home can clearly improve the quality of the time these people remain in their home (see [9] - [11] for discussion of well-being factors for people suffering from any type of impairment) as well as prolong their time at

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home.

Poor mobility and the resultant danger of falling is a major difficulty for people with NDD as it is for many frail aged people. Inclusive design documents refer to building characteristics that can make a substantial difference in reducing the risk of falling for those with mobility difficulties and reduce confinement for those in wheelchairs. Building characteristics inherent in inclusive design that accommodate mobility difficulties include:

- level thresholds
- no changes in floor level between sleeping, eating and washing areas
- no sharp shadows
- the ability to increase lighting levels
- the ability to install grab rails
- the availability of storage space for walking aids
- a hobless shower.

To enable a wheelchair to be used inside the home, then inclusive design should also include the following building characteristics:

- adequate space to transfer to and from a wheelchair
- the availability of wheelchair storage
- an appropriate height for fittings and fixtures such as light switches and taps.

A key advantage of inclusive design is that it is readily adaptable thus enabling supporting building elements to be installed or removed in response to changes in the personal functioning of the occupant. There is no implication that inclusive design features should induce rather than respond to dependency.

M.Powell Lawton was an influential contributor to research that related the quality of the environment to people's changing capabilities as they age [12]. His work reinforced his stated position that everyone has a right to live in a decent environment. This paper utilizes Lawton's [1] position regarding a decent home environment to consider whether the design of the typical home environment of people with NDD in Perth can be considered 'decent'. Lawton [1] developed the model (referred to as the ecological model of aging) shown in Fig. 1 to assess the occupant's satisfaction with the home environment. This model is used to analyse the links between the functional ability of a person with NDD and building characteristics. Although Lawton's model was particularly developed for environmental gerontology it is appropriate to any group that may not be fit and healthy.

In Fig. 1, the vertical axis represents personal competence or biological and cognitive well-being ranging from low at the origin to high. On the horizontal axis, environmental press is the extent to which the environment requires a response from the person. This ranges from minimal or weak responses on the left to strong responses on the right. Lawton's [1] model puts forward a direct relationship between 'personal competence' and 'environmental press'. That is, people whose personal competence is low require an environment that does not

expect much of them, whereas more competent people would be less challenged by, and therefore more responsive to, higher demands from their environment.

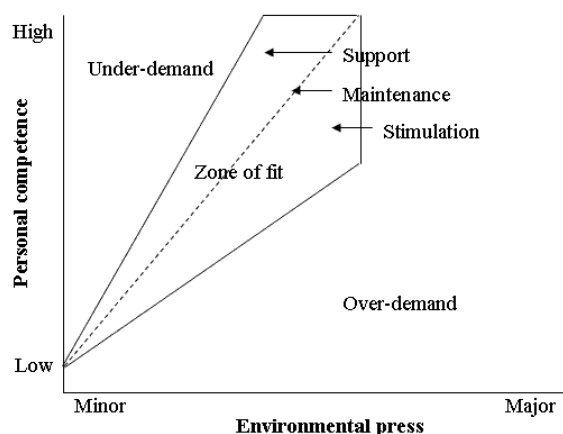


Fig. 1: Lawton's ecological model of aging showing personal competence and environmental press

Also shown in Fig. 1 is a range of possibilities either side of the upward-sloping competence-press function. This 'zone of fit' shows stimulation (to the right) and support (to the left). Stimulation describes the experience when some sort of unfamiliar activity or unexpected delight is present. Support describes the experience when there is a modification to the environment to allow a lesser demand on the person in order to satisfy needs. This support could be a physical modification, such as railing, or the provision of a service, such as showering by a paid carer.

Negative affects such as stress, or maladaptive behaviour, can occur if environmental press is greater than the level of personal competence (over-demand). If personal competence exceeds environmental press (under-demand), then a person may feel deprived and unnecessarily dependent. An extension to this model is tested and the results presented and discussed in Section IV.

III. DATA AND METHODOLOGY

In March 2007, Giles and Lewin [13] conducted a postal survey in Western Australia of people with MS, MND, PD and HD based on member lists from disease support agencies and client lists from home care service providers. The survey asked wide-ranging questions related to the individual's functioning and home support needs. The responses from the postal survey were encoded into ASCII format then imported into data analysis and statistical software Stata Version 9 [14]. This paper looks at responses related to mobility as well as responses regarding whether or not the individual had modified their home and what these modification were, as well as whether or not they had moved to a different home and the number of reasons for moving.

IV. RESULTS AND DISCUSSION

The finalised dataset of survey responses contains 1,095 observations (representing a response rate of

approximately 54%) and 429 variables, many of which are categorical or dummy variables. In this paper, the dataset used in the analysis includes only those respondents who reported living in a house, a unit/flat or an independent living unit in a retirement village (n = 1,058). Excluded are 28 respondents who either did not report their type of home or lived in some type of communal facility. The data can be disaggregated by differences in respondents' mobility, ranging from those having no trouble walking to those who are bedridden. The data can also identify those respondents who had modified their home and what types of modifications were made, and those respondents who had moved to a different home and the various reasons for moving house.

More than half of the respondents (n = 556) had modified and/or moved to a different home. Forty-four percent of respondents had modified their home (n = 473) and about twenty percent had moved house (n = 199). Approximately 11% of respondents had both moved into another home and made some modifications to it (n = 116).

A variable for home changes was constructed from the move and modify information. That is, the number of home changes is derived from the number of modifications made to the home and the number of reasons given for moving. This has enabled Lawton's [1] model, introduced earlier, to be reinterpreted using the survey data for those respondents who made home changes.

Fig. 2 shows that there is an inverse relationship between higher mobility and the average number of home changes (number of modifications and number of reasons for moving). In other words, as mobility deteriorates, modifications related to housing increase. For example, the trend line shows that as mobility declines from using aids inside the home (mobility level 3) to using a wheelchair with the use of arms (mobility level 2), the number of home changes increases from 2.29 to about 2.95, on average.

In terms of Lawton's model, Fig. 2 shows level of mobility as a proxy for 'personal competence' with declining mobility akin to decreasing competence. On the horizontal axis, Lawton's 'environment press' becomes 'environmental support'. This is measured by the average number of housing modifications. Increases in the number of housing modifications reflect greater environmental support and lower environmental press.

In Fig. 3, the relationship between mobility and the average number of home modifications per respondent is shown (measured on the left vertical axis) together with the number of respondents making specific modifications (measured on the right vertical axis) at each level of immobility (shown on the horizontal axis). Note that in Fig. 2, mobility level ranges from 1 (bedridden or using a wheelchair with limited or not use of arms) to 6 (no trouble walking), and in Fig. 3, immobility level ranges from 1 (no trouble walking) to 6 (bedridden or using a wheelchair with limited or not use of arms).

Four specific modifications are shown in Fig. 3 – changes to the bathroom, the addition of rails, the addition of ramps, and the removal of steps and the levelling of

floor surfaces. It can be seen that the number of respondents installing rails increases considerably as mobility declines from having no trouble walking (mobility level 1) to using aids inside and outside the home (mobility level 4).

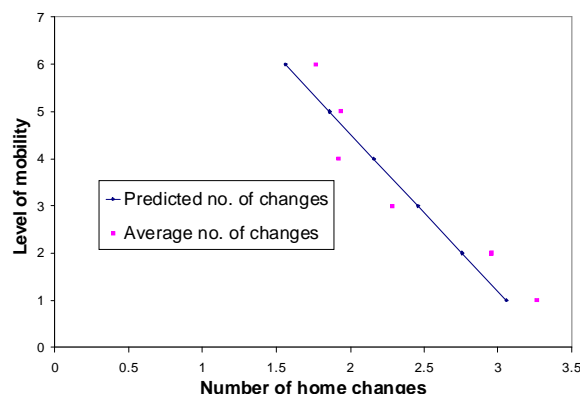


Fig. 2 Relationship between personal competence and environmental support

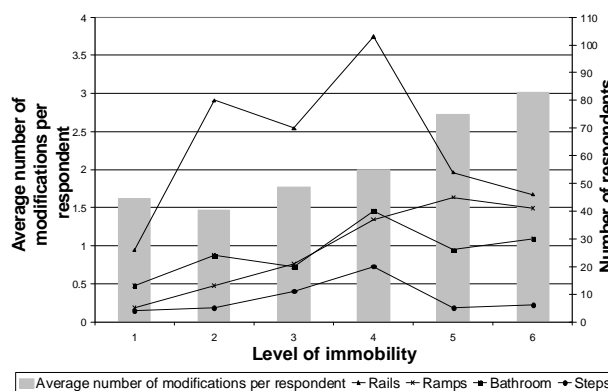


Fig. 3 Home modifications and mobility

People in wheelchairs have little need for rails so fewer respondents at mobility levels 5 and 6 report installing rails. Some individuals use their wheelchairs for moving about the home but rely on fixed railings to transfer to the toilet, a bed or a chair. Occasionally rails are removed when home occupants become bedridden or have limited or no use of arms.

The number of respondents who install ramps increases as mobility declines. Ramps may become necessary if individuals start having trouble walking (going up steps or across thresholds) or using aids, such as a walking frame, inside the home. Ramps are very necessary once a wheelchair is being used. Mobility level 6 includes people who use wheelchairs and have limited or no use of their arms as well as people who are bedridden. In both cases, the need for movement about the home or into and out of the home is quite low.

The number of respondents making changes to steps and levels within and outside the home follows a similar pattern to that for ramps. Bathroom modifications include removing the hob from a shower recess, changing the bath/shower to a hobless shower, changing the taps, widening the doorway, removing the shower screen and

installing rails. As shown in Fig. 3, the number of respondents who make changes to their bathrooms peaks at mobility level 4.

A neglected aspect of home modifications relates to the fact that most people with NDD have compromised respiratory systems and consequently may have problems with breathing. These problems can be exacerbated by dust and noise arising from building works. Moreover, there is evidence that volatile organic compounds (VOC), commonly found in typical house paints and varnishes, impact on the immunologic and neurologic functions. Spengler [15] points out that for those people with compromised immunological and neurological systems, including the frail aged, VOC are particularly damaging. Further, it is this group of vulnerable people who spends the majority of the day at home and may not be inclined to use or have access to good natural ventilation, thus compounding potential breathing problems.

V. CONCLUSION

Although Lawton's [1] model is a simplification of a complex reality, it has been shown here to provide a framework for describing the relationship between the deterioration in mobility that characterises the functioning of people with NDD and their increasingly complex physical needs in the home. The results of the NDP in Perth, Western Australia, show that house design is clearly one of the factors involved in enabling people with NDD to manage their difficulties whilst remaining in their homes. As many of the issues concerning the housing experience of people with NDD can be related to the frail elderly it is concluded in this paper that inclusive design should be considered in the design of all housing. This will benefit not just the 85 in 100,000 Australians with NDD diseases but also up to 23,000 in 100,000 of Australia's ageing population [16].

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