Fashioning Identity: Inclusive Clothing Design and Spinal Cord Injury

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Abstract
The failure to design clothing to meet the needs of people with spinal cord injury marginalises them through prevention of normal expression of identity and encouragement of discriminatory social perception.

Clothing has been designed historically for the standing, mobile figure. It provides the proximal interface for the body and its extracorporeal environments and the medium for expressed and perceived identity. When the body is catastrophically injured, the efficacy of clothing in portrayal of the self is greatly reduced, while its protective function is compromised because it becomes capable of inflicting further harm. Regular clothing, when worn by a wheelchair user, engenders problems in medical, functional, aesthetic and emotional domains, which adversely affect identity, self expression and social perception.

An online questionnaire was completed by 100 participants, selected by passive snowball sampling. It was found that many of the needs of people with spinal cord injury were not being met by current available and affordable clothing solutions and that clothing design overlooked key concerns. An analysis of clothing products marketed to wheelchair users revealed inadequate needs analysis and market testing and insensitive use of marketing strategies. Both innovative clothing design and marketing strategies will encourage social inclusion of wheelchair users.

Keywords
Wheelchair, Paralysis, Spinal Cord Injury, Clothing, Dressing, Aesthetics, Pressure Sores, Medical Disability.

Introduction
Inclusive design, available for broad, accessible use, cannot be easily translated into fields where individuality and personal choice are critical. Clothing for wheelchair users with spinal cord injury, when designed broadly for accessibility, becomes impersonal, inefficient and potentially life threatening. For clothing to be inclusive of consumers with spinal cord injury, specific needs of this market must be understood and met by design solutions.

Damage to the spinal cord can result in permanent injury and paralysis. It not only affects mobility of the limbs but also internal functioning of the body [1] resulting in loss
of “motor-power, deep and superficial sensation, vasomotor control, bladder and bowel control and sexual function” [2].

Clothing, as the body’s most proximal environment, is inextricably linked with personal identity and other significant contexts of human existence. It is a medium for transmission of information about the wearer [3] and mediates the interface of the human being and its environmental and social contexts [4].

Whether we like it or not, clothes have a bearing on our acceptability by society […] Dressing ourselves gives us independence, and clothes express our individuality; however minimal the ability, everyone should be encouraged to dress himself and choose his own clothes. [5]

However, most current clothing designs do not enable the independence of the wearer but instead often render them more reliant on their carer. When the body is catastrophically damaged, as is the case with spinal cord injury, the reflexive relationships between body, sense of self and the environment are significantly disturbed. Critical for user-oriented design of clothing, is an understanding of how the usually accepted view of identity, expressed through clothing, differs because of the radically altered capacities of wheelchair users.

With damaged embodiment and forced use of tools such as wheelchairs, the societal view is also changed [6]. The visibility of spinal cord injury may elicit greater social stigma than less visible conditions such as diabetes, epilepsy or cardiovascular disease [1].

People whose mobility is limited after spinal cord injury, may find that innate capacities are also disrupted or lost. Walking, continence management and unassisted breathing may no longer be possible. Paralysis fundamentally changes embodiment so that many skills for mobility, transfer, toileting, eating, writing and dressing need to be re-learned.

Rebuilding the embodied self after such disruption is an extremely difficult task. A person's self-image has been developed over a lifetime in relation to particular social ideas and in terms of a body with certain skills, abilities and appearances. [7]

In order to adequately respond to user needs, a cohesive needs analysis is required. This would enable development of effective user-oriented design of clothing products for people with spinal cord injury that would combat issues of social exclusion.

**Method**

The research¹ was conducted in two parts:
- A survey analysis of user needs
- An analysis of clothing products marketed to wheelchair users

These studies investigate medical, functional, aesthetic and emotional concerns that wheelchair users have in relation to their clothing and explore existing design solutions.

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¹ This research study was approved by the Human Ethics Committee at the University of Sydney, reference number 12271.
User Needs Analysis

In the medical rehabilitation literature [8] the discussion of clothing needs of wheelchair users is largely speculative, drawing on clinical experience and beliefs of interested parties. The quantitative needs analysis provided an empirical insight into the clothing needs of people with spinal cord injury.

Existing Product Analysis

User responses revealed that currently available clothing products were not meeting market needs. The product analysis reviewed currently available clothing advertised online for the wheelchair user market.

Participants

User Needs Analysis

One hundred wheelchair users completed the survey (52 female; 48 male). The online survey yielded a 26% response rate. Participants ranged in age from 21 to 73 years. The average age of respondents was 42.8 (SD = 13.9). Of these respondents, 67 used manual wheelchairs and 33 used electric; 37 respondents had cervical injury, 26 thoracic injury, 22 lumbar injury, 4 sacral injury and 11 respondents used a wheelchair because of conditions other than spinal cord injury. The number of years of injury ranged from less than one year to 60 years, with an average of 17 years (SD = 14.6).

A passive snowball sampling technique [9] was used. Passive snowball sampling requires no direct contact between the researcher and potential participants so that participants cannot feel coerced into involvement in the study. Survey links were published by organisations associated with wheelchair user groups in magazines, websites and promotional materials. The size of the final sample was constrained by time limits and could not proceed to response saturation. Two responses were excluded because of illogical bias to one numerical category. The survey was available on the internet and could be reached globally, however, responses were received predominantly from Australia and the United States of America, with smaller numbers from other countries. Although designed on the basis of Heckathorn’s model of respondent driven sampling [10], sample representativeness could not be evaluated because of the way the links were circulated over the internet. Heckathorn’s model ensures that the number of respondents is a true but scaled depiction of the distribution of the population. The sample obtained in this study, although possibly representative of the Australian population, cannot be considered to be representative of the global population.

Existing Product Analysis

To investigate design features of existing clothing for wheelchair users, extensive online searches were undertaken through Google searches using combinations of the following terms: wheelchair, clothing, paralysis, disability, dressing, paraplegia, quadriplegia and spinal cord injury. Additional design solutions available in dressing guides and patterns
proposed in occupational therapy or rehabilitation literature were also reviewed. Focus was placed on companies specifically targeting wheelchair users.

**Materials**

Survey participants were provided with a purpose-designed questionnaire which ensured anonymity. Questions were developed on the basis of issues identified in medical literature and discussion with rehabilitation personnel.

Twenty-six questions were developed around the themes of function, aesthetics, emotion and medical issues. To evaluate content validity of the measurement procedure, for the purpose of the research, the questionnaire items were reviewed by a Specialist Rehabilitation Physician, an Occupational Therapist and a Clinical Health Psychologist and representatives of two involved organisations; the Spinal Injuries Association and the National Spinal Cord Injury Association. Reviewers were unanimous that the questions were unambiguous and permitted description of varying levels of medical, aesthetic, functional and emotional experience.

Demographic data collected included age in years, gender, date of injury, vertebral level of injury and wheelchair type (electric, manual or sports). Table 1 describes the content and structure of the questionnaire in the other domains.

<table>
<thead>
<tr>
<th>Table 1: Response Collection</th>
<th>Information Collected</th>
<th>Quantification method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical</td>
<td>Pressure sore experience, Temperature control problems Emergency undressing</td>
<td>Yes or No Likert scale ranging from 1 = not difficult to 5= very difficult No, Sometimes, Often or Mostly</td>
</tr>
<tr>
<td>Functional</td>
<td>Ease of dressing, access for continence management, comfort &amp; problems with wheelchair Dressing time, Assistance in dressing or transfer</td>
<td>Likert scales ranging from 1 = not difficult to 5= very difficult 30 mins, 45 mins, 1 hr or &gt;1 hr None, 1 assistant or &gt;1 assistant</td>
</tr>
<tr>
<td>Aesthetic</td>
<td>Smart/Sloppy, Attractive/Unattractive, Beautiful/Ugly, Concern about catheter line or bag</td>
<td>Semantic differential responses were quantified using five-point Likert scales. N/A, Yes, No or Sometimes</td>
</tr>
<tr>
<td>Emotional</td>
<td>Happy/Sad, Hot/Cold, Wet/Dry, Embarrassed/Peaceful, Interesting/Dull, Healthy/Unhealthy, Confident/Worried, Calm/Frustrated</td>
<td>Semantic differential responses were quantified using five-point Likert scales.</td>
</tr>
</tbody>
</table>

Differences between responses of participants in demographic categories and relationships between medical, functional, aesthetic and emotional responses were assessed.
Procedure

User Needs Analysis

Subjects were recruited through organisations representing wheelchair users. Survey Gizmo, an online survey tool, was used to format the questionnaire so that it could be electronically distributed. The online questionnaire was accompanied by an information statement outlining the project and response instructions. The information statement clearly outlined that voluntary consent was assumed upon submission of the questionnaire response.

Existing Product Analysis

Products were analysed according to whether they met criteria derived from the survey responses of wheelchair users. The marketing strategies utilised by these companies were also reviewed.

Statistical analysis

Statistical analyses of survey responses were performed using SPSS quantitative analysis software (SPSS for Mac, Version 17.0, 2008 SPSS inc. Chicago, IL, USA). Group differences were examined using regression, t-tests and chi-square analyses. These tests were conducted to examine the variance and covariance of the medical, social, functional, aesthetic and emotional indices of the questionnaire.

Regression analysis was used for analysis of continuous variables (e.g. age) and analysis of variance or independent sample t-tests with discrete variables (e.g. gender). Sequential multiple linear regression analysis was undertaken using two predictors, injury location and gender. Chi-square ($\chi^2$) measures the difference between obtained and expected outcomes with discrete categorical data. Simple linear regression analysis was used to investigate whether years with injury, age and difficulty with purchasing clothes influenced responses on other scales. Simultaneous multiple linear regression was used to examine whether years with injury, wheelchair type and age predicted responses on other questionnaire items amongst people of a similar age, gender and injury level.

Results

The needs analysis was completed prior to the product analysis so that the extent to which these products addressed user needs could be evaluated.

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3 The invaluable guidance and assistance in preparation of these analyses of Alex Russell, School of Psychology, University of Sydney, is acknowledged with thanks
User Needs Analysis

The analysis of user needs revealed that:

- 41% of respondents experienced a pressure sore caused or exacerbated by clothing.
- 15% were satisfied with time taken to undress in an emergency; 85% expressed concern with time to undress (36% sometimes, 28% often, 21% mostly).
- 53% of respondents required no assistance in dressing, 43% required one person to assist and 4% required two assistants.
- 57% of respondents did not require assistance in transfer in and out of the wheelchair, 37% required one assistant and 6% required two.
- 55% of those requiring catheters were concerned about the appearance of their catheter line/bag, 21% were sometimes concerned and 24% were not concerned. 79% had experienced difficulty accessing their catheter because of clothing and 21% had experienced no difficulty.

Injury Level

Regression analysis was used for analysis of relationships between injury levels and other variables. The higher the level of injury the more likely respondents were to report difficulty in purchasing clothes that allowed for ease of dressing \((t(87) = -2.43, p<0.05)\) and caused no skin problems \((t(87) = -2.48, p<0.05)\). People with higher injuries reported greater difficulty with purchasing clothing that enabled continence management \((t(86) = -2.45, p<0.05)\) and appeared businesslike \((t(87-6) = -2.45, p<0.05)\). They also reported their clothing to be dull \((t(85) = -2.24, p<0.05)\) and described greater feelings of sadness about clothing \((t(87) = -3.02, p<0.01)\), required longer dressing time \((\chi^{2}(9)=19.24, N=89, p<0.05)\), and more assistance with dressing \((\chi^{2}(6)=31.56, N=89, p<0.001)\) and transfer in and out of the chair \((\chi^{2}(6) = 32.50, N=89, p<0.001)\). No significant relationship was obtained between level of injury and regulation of body temperature, although it had been expected that temperature control may be a problem for respondents with high level injury as they experience loss of functions like shivering and sweating.

The higher the injury level, the greater the loss of mobility and consequent reliance on carers for basic needs. Higher levels of injury led to greater changes in the body shape, as stomach muscles became flaccid and legs wasted. An increase in abdominal span was apparent even when other areas of the body remained lean, making it difficult to fit clothes to the body. The data revealed that people were very keen to conceal or camouflage the stomach area but usually did so by purchasing larger sizes with the result that clothes that did not fit well, made them look bigger and posed greater risk of pressure sores.

Difficulty in Buying Clothes

As mean score for difficulty in buying clothes increased, people were more likely to respond that they felt unattractive \((t(97) = 6.97, p<0.01)\), sloppy \((t(97) = 6.54, p<0.01)\), dull \((t(96) = 2.26, p<0.05)\) and ugly \((t(97) = 3.94, p<0.01)\) in their clothes. They were more likely to report that they felt their clothes were difficult to wear \((t(97) = 5.89, p<0.01)\) and unhealthy \((t(95) = 5.06, p<0.01)\) and more likely to respond that they were sad \((t(98)\).
frustrated $[t(98) = 2.33, p<0.05]$ and embarrassed $[t(98) = 4.00, p<0.01]$ about their clothes.

**Gender**

Women had more difficulty than men purchasing clothes that did not rub on the wheels of the chair $[t(96) = 2.02, p<0.05]$. Women also found it more difficult to buy clothes that made them feel attractive $[t(86) = -2.13, p<0.05]$.

**Catheters**

People with higher injury level were more concerned about appearance of catheters $[\chi^2(9) = 33.93, N=89, p<0.001]$ and had experienced difficulty accessing catheters in emergency $[\chi^2(6) = 18.71, N=89, p<0.05]$. However, no significant difference was found between high and low responders regarding sensitivity to appearance or function of catheters, although high responders reported greater sadness $[t(31) = -2.42, p<0.05]$, worry $[t(31) = -2.14, p<0.05]$ and frustration with them $[t(31) = -2.15, p<0.05]$.

**Years with Injury**

Where age, gender and injury level were controlled, results showed that people adjust to their injury over time. As the years passed, they found it easier to obtain clothing with access for continence management $[t(93) = -3.12, p<0.01]$ and were more likely to respond that the function of their clothes was easy $[t(93) = -2.11, p<0.05]$.

**Age**

As age increased respondents reported greater difficulty in buying clothes that were easy to take on and off $[t(97) = 2.17, p<0.05]$.

**Wheelchair Type**

Amongst people of similar age, gender and years with injury, people using a manual wheelchair were more likely to respond that it was difficult to buy clothes that allowed for ease of dressing $[t(90) = 5.45, p<0.05]$, caused no skin problems $[t(90) = 5.77, p<0.01]$, kept them at the right temperature $[t(90) = 6.47, p<0.05]$ and did not rub on the chair wheels $[t(88) = 5.59, p<0.05]$ but were also more likely to feel sad $[t(90) = 4.83, p<0.05]$ about their clothes.

**Existing Product Analysis**

Two problems emerged in existing clothing design for wheelchair users. Some designers, having focussed on solutions for one specific client, attempted to generalise their designs to others without analysis of the differing needs of users. Conversely, some attempted to design for a wide population, encompassing different needs, but failed to address issues specific to subgroups of disability.

Widely available clothing solutions for wheelchair users focussed predominantly on functional and medical issues (often indiscreetly) and placed less emphasis on
emotional, expressive or aesthetic requirements of the clothing. In doing so, they often failed to address important expressive issues of sexuality and identity and produced negative images of asexuality, inelegance or unattractiveness [1].

Many solutions do not consider the relationship between body and wheelchair. Designers tend to overlook knees and ankles where pants are often too short or become bunched and creased and appear oblivious of abnormal creasing and bunching of shirt designs e.g. where the yoke causes the shirt to hang diagonally from the shoulders, or crease across the torso.

These findings are congruent with those uncovered in the user needs analysis. The existing clothing market for regular clothing, though broad and diverse, does not make provision for wheelchair users, leaving them with few, if any, clothing options that address the issues described in the user needs analysis.

**Discussion**

Currently available clothing designs are not appropriate or successful for wheelchair users with spinal cord injury. The danger of socially equalising all bodies under the guise of social inclusion threatens to exacerbate exclusion. In this case, regular clothing designs are cumbersome, designed for standing figures, ill-fitting, inefficient and often generate further health threats requiring medical vigilance.

The trauma of spinal cord injury triggers feelings of loss about physical ability and identity. A pervasive sadness was evident in relation to loss of clothing normally worn before injury or clothing that was ‘right’ for the user because it expressed identity. The most common solution was to alter or tailor-make clothing but often these alterations were undertaken by amateurs and created other safety or aesthetic challenges. Therefore, there is a need to provide this market with clothing that does not require alteration but adequately expresses individual identity. An issue of safety which does not appear to be addressed anywhere is the safety of carers. The lifting and moving of heavy bodies in the dressing process could be avoided with innovative design solutions that also consider their needs.

Existing clothing designs do not meet the disparate needs of users associated with level of injury, gender, wheelchair type and age and designers extrapolate inappropriately from single cases to the whole disability market. The lack of holistic design solutions encompassing all needs implies a lack of research and inadequate market testing of developed products. A consequence for wheelchair users is that their clothing choices become limited to designs that are easy to put on, least likely to cause pressure sores and provide ready access for skin and catheter management i.e. usually tracksuit pants and t-shirts. This lack of choice so limits their means of individual expression that they risk social marginalisation because the casual dressing style leads them to be viewed in a uniform way by the wider population as ‘disabled’ rather than individual.

Clothing products, marketed to wheelchair users, are often modelled by mobile people, fitted to standing mannequins or modelled by people crossing their legs in the wheelchair (a position likely to create pressure sores). Some designs have no features specific to wheelchair users; instead wheelchair users are targeted as a market for able-bodied products. These sorts of marketing strategies are demeaning and, in some cases, offensive. The time where people are most in need of a good range and
adequate choice in clothing is in the early stages after injury when they are most emotionally affected by their injury. It is very important that feelings of physical loss are not further exacerbated by such a huge restriction in choice of clothing that their expression of identity is compromised.

Thorough research of user needs enables designers to work within well established constraints. This type of research is capable of providing for wheelchair users the same opportunities for exciting, unique and innovative design solutions available to able bodied people.

Silos of specialist expertise created by the information explosion mean that valuable and potentially productive interfaces such as medicine and fashion design remain relatively unexplored. This research identifies the importance of collaboration between different fields of expertise in order to resolve emerging social problems such as survival from catastrophic injury or increasing longevity of life.

**Conclusion**

Clothing is a tool to bolster self-esteem, explore fashion, and camouflage faults although its most important function is the construction of an image with context-specific meaning. Wheelchair users need the same opportunities to create effective and meaningful personal images that able bodied people take for granted.

At this stage it is not possible to project with accuracy what may happen in the future with new technology such as smart fabrics or wheelchair robotics. However, it is possible that by providing clothing that meets all the functional and safety requirements of a wheelchair user, greater availability and choice of clothing that expresses identity may follow, thus achieving improved social inclusion. How we proceed towards health and social sustainability depends upon moral perceptions such as equity and collaborative input from disparate fields of endeavour e.g. medicine, psychology, design and government. Thus, it is the goal of creating inclusive clothing design that fuels socially innovative design solutions.

To date existing design solutions are speculative and poorly market tested. The solutions themselves often exacerbate problems in other areas. Thorough, well considered clothing designs that deal with all four categories of functional, medical, aesthetic and emotional needs will eliminate many clothing-induced functional problems, reduce social stigma and self-deprecation thus achieving greater social inclusion, and make it possible to foster the kind of research at new interfaces that drives design innovation.

**Bibliography**


Mallgrave & W. Herrmann, Trans.). New York: Cambridge University Press


