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A needs analysis of clothing for people with spinal cord injury was conducted utilising a survey and focussed interviews of wheelchair users, carers and therapists. The survey was completed online by 100 participants and interviews were conducted with 20 participants to provide narrative detail. Survey respondents ranged in age from 21 years to 73 years, 52 were female and 48 were male. The number of years that respondents had been injured for ranged from less than one year, to 60 years.

It was found that all 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.

Respondents reported deep grief and feelings of loss over the inability to wear clothing that had been worn prior to their injury. Respondents reported that it was particularly difficult to purchase clothing that sat correctly on the seated figure but that was also attractive, fashionable, easy to put on and expressed their sense of self. Many respondents resorted to bespoke tailoring or clothing alteration to make clothing fit their needs. However, although tailoring provided the most appropriate solutions, there were a number of concerns about the cost involved in pursuing this option.

The data revealed that people were very keen to conceal or camouflage the stomach areas but usually did so by purchasing larger sizes with the result that clothes did not fit well in other areas of their body, looking “baggy” and not falling correctly. Furthermore, the large amount of excess fabric tended to make them look bigger and pose greater risk of becoming caught in the wheelchair or creating pressure sores. Because of the frequency and danger of pressure sores, many wheelchair users accepted reduced expression of identity in order to protect themselves from this risk.

Wheelchair type appeared to make a difference to the perceived effectiveness of clothing. People using a manual wheelchair had increased difficulty in purchasing some types of clothing and with clothing getting caught in or worn out by the chair wheels. For these functional reasons they limit their choice of clothing and this affects both how they feel and the difficulty they experience in purchasing clothing.

Those respondents interviewed were very aware of how they were perceived by others, reporting that “everybody is looking at you” when using a wheelchair. These respondents sought clothing that functioned well but at the same time appeared to fit the perceived social norm. Respondents expressed that it would be ideal if the clothing could function appropriately for the wheelchair user but in a discreet way that allowed the clothing to appear ‘normal’.

Respondents often reported great difficulty with purchasing clothing as many shops and change rooms were inaccessible. People often ensure upon purchase that an item can be returned or exchanged if the item does not fit or fall correctly, as it must be tried on at home. A number of respondents instead chose to shop online.

Opinions varied greatly on acceptance of tools as part of identity: many respondents considered their wheelchair and other assistive devices to be integral parts of their identity whereas other respondents viewed the wheelchair as purely a mode of transport. This makes it difficult to integrate person and clothing with the wheelchair as, for some people, it is important that they do not feel attached to or associated with their wheelchair.

What was clear from the research data was that identity is complex. The time where people were in most need of a good range and adequate choice in clothing was in the early stages after injury when they are most emotionally affected by their injury. It is critically important that feelings of physical loss are not further exacerbated by these huge restrictions in choice of clothing because expression of identity becomes compromised.