

Urinating when away from home

A major physical and mental problem for women with neuromuscular diseases A neglected issue

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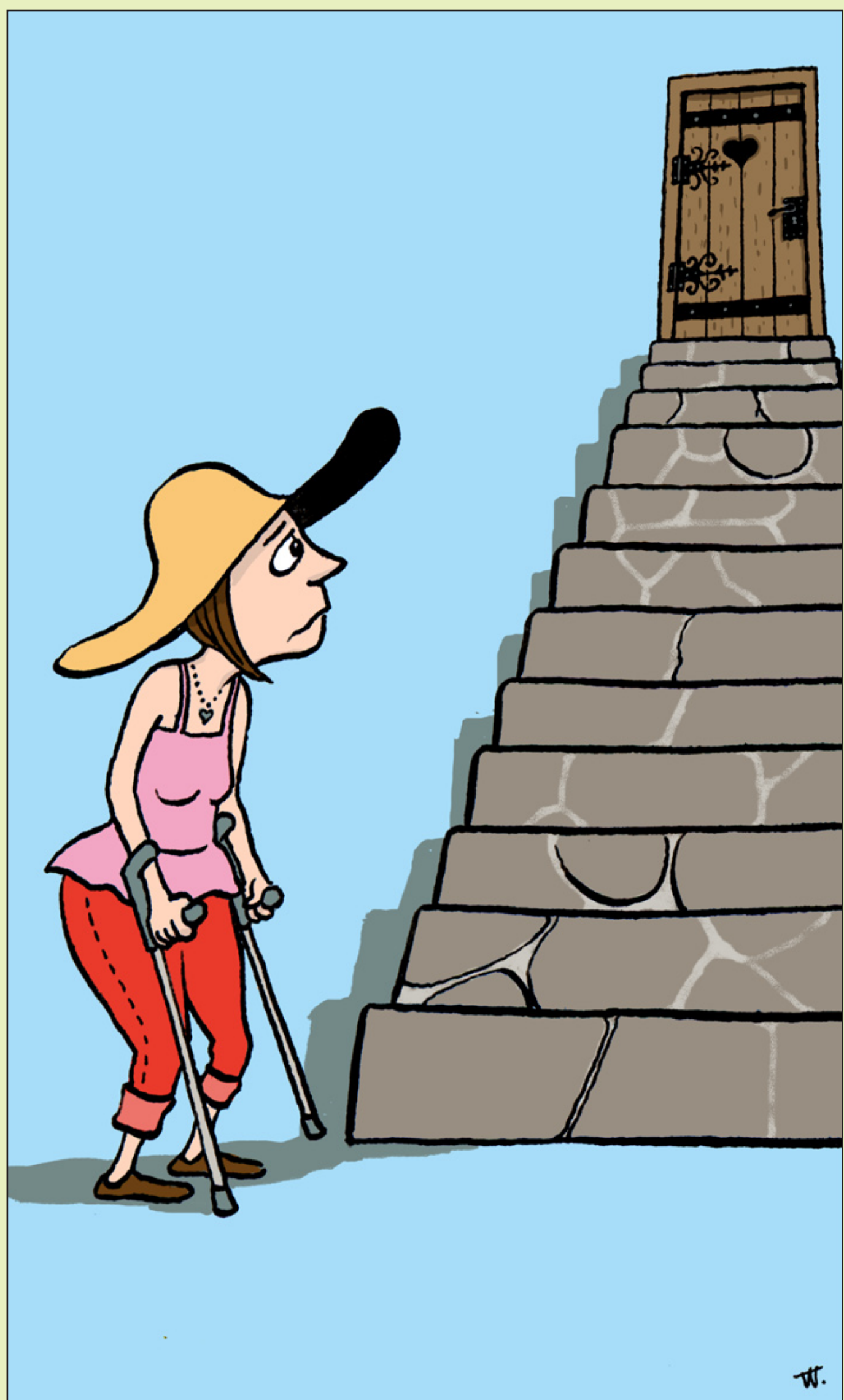
Aim

The purpose of this study was to highlight

- the size of the problem of using a toilet when away from home among females with neuromuscular diseases
- what women with neuromuscular diseases do to be able to leave home when not being able to use a standard toilet
- how the problem influences the daily lives of the women

Background

People with neuromuscular diseases often have problems using a standard toilet due to difficulties in getting on and off the toilet, opening and closing doors and climbing stairs. Women have more problems than men since they do not have the same opportunities to use a urinal bottle. Furthermore, many wheelchair dependent women also need practical help to be transferred to and from the toilet and to get dressed. These difficulties could inhibit participation in life outside their homes and reduce their quality of life in general.



Methods

A questionnaire was developed and sent to all 857 women above the age of six, registered with The National Rehabilitation Centre for Neuromuscular Diseases in Denmark

The questionnaire included questions about

- functional level
- need of technical aids
- possibility of physical and social participation
- ways of solving the problem of not being able to use a standard toilet
- a VAS-scale for scoring the women's perception of the size of the problem

The women were divided into three groups according to their physical abilities as we assumed that the size of the problem was dependent on their functional level.

- The “wheelchair dependent group” was 100% dependent on a powered wheelchair, and many were also dependent on practical personal assistance.
- The “middle group” was able to walk to some extent. They had different problems such as climbing stairs, opening doors and/or getting up from toilet seats.
- The “independent walking group” was able to walk independently, climb stairs and use standard toilets.

Conclusion

The results confirm that having difficulties in using a toilet when away from home is a considerable problem among women with neuromuscular diseases who are wheelchair dependent or have reduced walking abilities. The more disabled the bigger the problem as they have fewer opportunities to use a standard toilet.

The most used solutions are:

- retaining urine for several hours
- using a diaper.

Less used solutions are:

- catheter
- toilet solution in their car
- self-made urinal bottles and special clothing arrangements

The study confirms that the problem has a negative influence on their quality of life. It is a physical strain not to be able to drink sufficiently and to have to retain urine for extended periods of time. It is a mental pressure always having to plan where to use a toilet and always depending on help with toilet visits.

Results

The questionnaire was returned by 626 women (73%). The respondents represented all the genetically determined neuromuscular diseases, Myasthenia Gravis and ALS.

■ 147 people were in the “wheelchair dependent group”

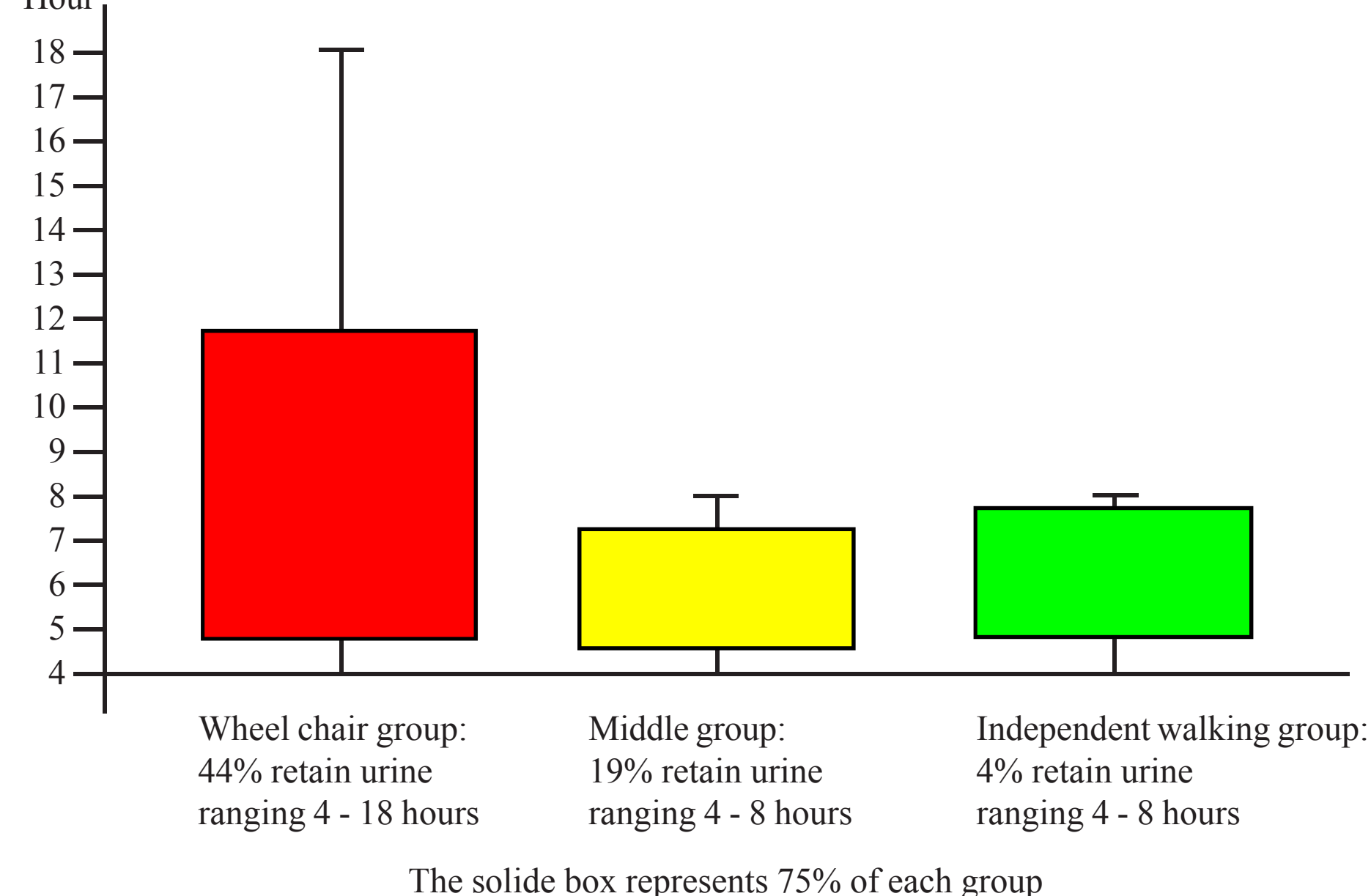
■ 240 people were in the “middle group”

■ 241 people were in the “independent walking group”

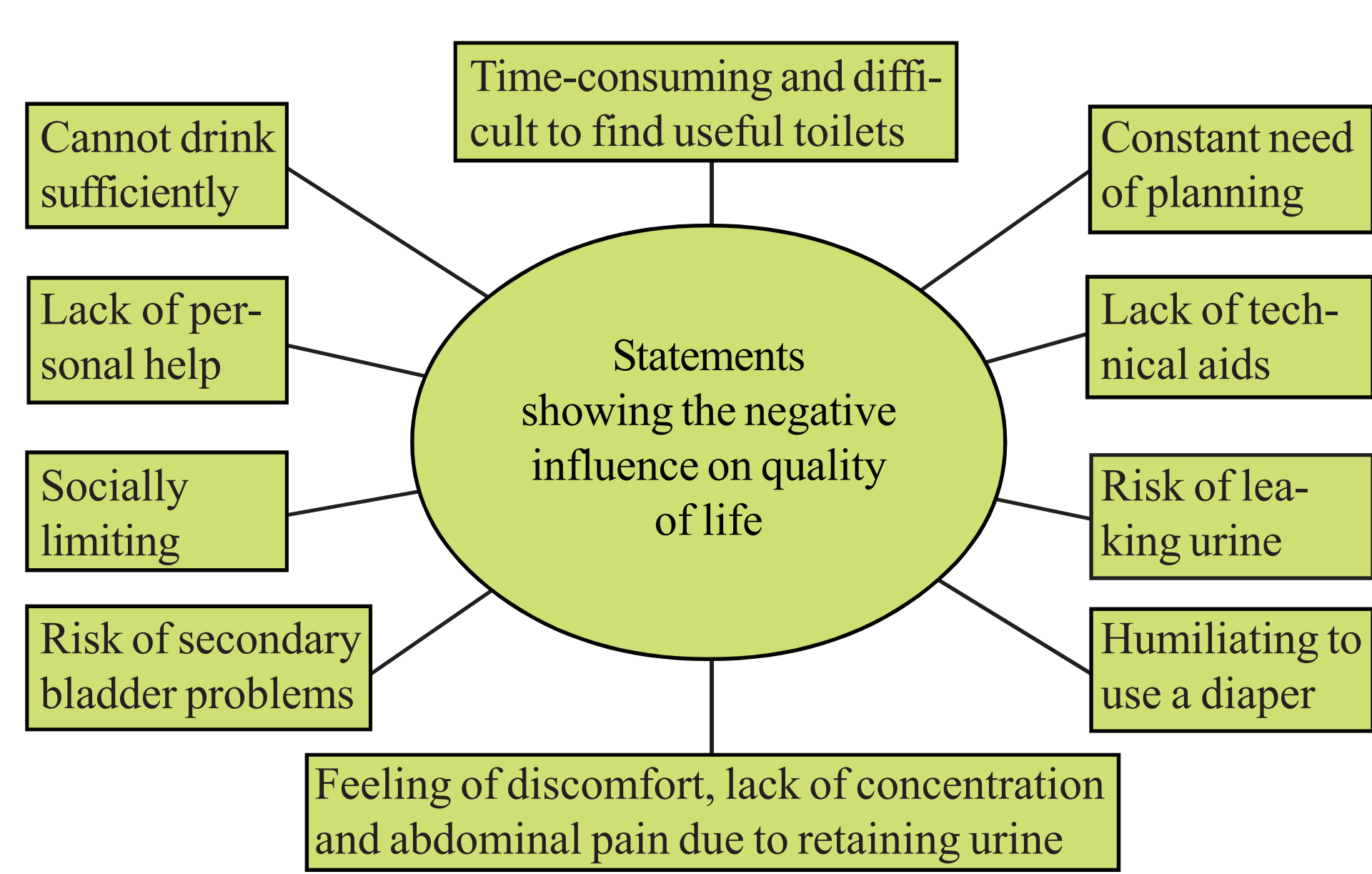
It was a considerable problem for women who were wheelchair dependent or had decreased walking ability not being able to use a standard toilet



Refraining from using a toilet for several hours was the most common way to manage being away from home



The women presented physical and mental statements showing the negative influence on their quality of life, when not being able to use standard toilets



Among all the respondents (n=626):

- 125 used a diaper. In the wheelchair dependent group it was 55/147, in the middle group it was 55/240 and in the independent group it was 15/241
- 25 used catheter, all in the wheelchair dependent group except for 4 people
- 13 had a toilet solution in their car, all in the wheelchair dependent group except for 3 people

Some of the women had different self-made arrangements to make it possible to urinate such as self-made urinal bottles and special clothing arrangements

Discussion and perspective

Being able to urinate when you have to is a basic need and therefore it is crucial to focus on this problem in relation to women with neuromuscular diseases. Both practical and medical solutions are required to assure that difficulties in urinating away from home do not decrease the social life of women with neuromuscular diseases.