

Home

is where the heart & the stuff is..

Introduction

The 'Better at Home' campaign lobbies for the right for children and young people with long-term complex health care needs, wherever possible, to be able to receive timely, high quality and effective care in their own homes. Evidence shows (and 'common sense' tells us) that almost always children and their families prefer for care to be provided within their home. However, home is not the binary opposite of hospital. Children's nurses caring for children in their own homes need to think about how easy it is for families to be 'at-home' when their homes are changed by the invasion of medical technology, equipment and other 'stuff'.

Being at-home

Seamon (1979) talks of 5 pre-requisites of 'at-homeness'. **Rootedness** is connected to our spatial roots and our home being a place of departure and return. **Appropriation** is to do with possession, control and privacy. **Regeneration** relates to home being a place of restoration, physical and mental rest. **At-easeness** refers to us being free to able to be who we are. **Warmth** relates to the sense of friendliness, support and concern we experience at-home.

Technological challenge

The technology required to support children with highly complex needs shifts the aesthetic of home and challenges 'at-homeness'. Rooms can look, feel, smell and sound different. Room use is changed (living room to bedroom, space for carers, displacement of siblings) and engagement within space is changed (different boundaries for siblings). 'Stuff' (e.g. medical supplies "in big brown boxes" and technological and mobility aids such as chairs, ventilators and drip stands) intrude into the home. This can create a sense of dis-ease at home. Some families find it difficult to create a real sense of home where they can truly relax and be themselves and which is not disturbed by technology or professional carers.

Parents reclaiming home

As parents start to recognise the subtle and not so subtle ways in which their sense of home is being challenged, they take action through both explicit and unacknowledged acts to mediate the changes. They recreate at-homeness through creating havens of space (no-go areas for professionals) and lines of sight that are neither technologically dominated nor dominated by professional presence. They conceal equipment and "make the visible invisible". They also re-establish a sense that home (rather than hospital) is the central place in their lives and they develop confidence in both leaving and coming back home.

Conclusion

Home is much more than the physical place where the family resides. Through strategies of resistance and reclamation families re-create at-homeness. Children's nurses need to support families beyond the provision of resources and 'stuff' and consider how the sense of home and the aesthetic of home can be subtly and sometimes radically shifted.

References

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