Living with a Tracheostomy – support available and the impact on patient and family

C. Gaubert[1], E.Breckin[2], J.Schofield[2]

Bradford Teaching Hospitals NHS Foundation Trust 1; NIHR Yorkshire and Humber Patient Safety Research Collaboration 2;

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NHS Bradford Teaching Hospitals NHS Foundation Trust

BACKGROUND

- Increasing numbers of people now live at home with a tracheostomy, coping with the complexities and risks that these present.
- Little information is known about the support these people receive from healthcare services.
- Until now, in the United Kingdom, their views and experiences have not been gathered.

METHODOLOGY

- A benchmarking survey was undertaken to investigate existing community tracheostomy support services (questionnaire).
- Semi structured interviews were conducted with adults living with a tracheostomy and family members (n=6).
- Development of the interview framework was based on themes from the current literature about community-based tracheostomy care

NATIONAL BENCHMARKING REPORT ON TRACHEOSTOMY SERVICES IN THE UK

RESULTS

Themes in our analysis

- Types of Trache care tasks undertaken
- Training for discharge from acute trusts
- Patient Experience
- Family Experience

> "I'm alive, I can breathe, I can eat and drink!"

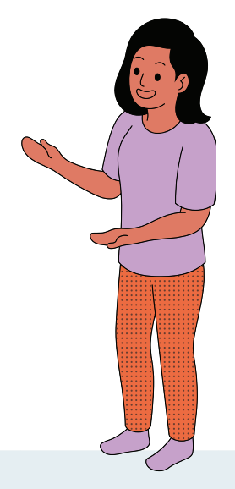
> "I felt prepared, but it was easier for us because of my nursing background."

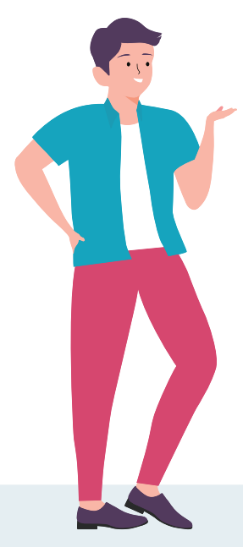
> "We do daily cares together mostly. At first it's frightening, a real eye-opener. There was no support or point of contact and we felt in the dark."

> "The best thing for her, but the worst thing for me. She can breathe now. Our house is not a home."

> "When you first get home you wonder 'Am I going to manage?'. Went to GP who admitted the trache 'was all new to me'."

> "Asked District nurses to be involved – they hadn't seen anyone with a trache before."





CONCLUSION

- Fragmented, inadequate specialist healthcare support exists nationally for people living with a trache, resulting in health inequalities.
- Individuals report feelings of vulnerability on discharge from acute Trust. A co-ordinated pathway is needed between acute care and community setting.
- Informal support networks are vital to cover gaps in healthcare services, but are potentially fragile.

IMPLICATIONS

This scoping exercise provides new information to benefit research teams and clinicians. It is the first time that this type of information has been gathered in the UK.

Participants now form a stakeholder group supporting future research.

Future work is needed to identify accurate numbers of people living with a trache, in order to inform service developments.

REFERENCES

NIHR | National Institute for Health and Care Research

Contact details
Cordy Gaubert
cordy.gaubert@bthft.nhs.uk

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