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ARTICLE



A life-changing event: patients' personal experiences of living with a long-term tracheostomy

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ABSTRACT

A tracheostomy is a commonly performed surgical procedure to alleviate some form of inadequate breathing. Tracheostomies may be temporary in the case of airway emergencies or may be for long-term access to airway and breathing depending on a patient's condition; in the case of the latter, this may have a major impact on a patient's life, one for which they are frequently unprepared. There is growing recognition that patients' views of their health care experience are an important component of quality of care. Through a deeper understanding of the challenges inherent in being a tracheostomy user, we sought via a two-stage study to inform the design of products for use by individuals with permanent tracheostomies. Stage one involved 10 participants taking part in in-depth interviews to understand the lived experience of long-term tracheostomy patients. Using thematic analysis, we found participants accepted the need for a tracheostomy but were keen to return to a life pre-tracheostomy. The restrictions the current designs of tracheostomy imposed was evidenced by the time required to spend on the daily care of their stoma and tracheostomy equipment, and by the significant restrictions on activities of daily living. Findings from stage one informed subsequent co-design workshops.

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Tracheostomy; long-term; adult; qualitative; community; quality of life

Introduction

A tracheostomy is a surgical intervention in which an opening is made in the trachea to create a stoma in order that intubation may take place to facilitate breathing, thereby circumventing the mouth, nose and throat. People who have had a tracheostomy fall into the group at times referred to as 'neck breathers' (McGrath et al. 2012; Royal Liverpool & Broadgreen University Hospital NHS Trust 2016). Within New Zealand and Australia, it is estimated that 7000 people

annually require tracheostomy surgery, resulting in the use of either temporary or permanent tracheostomies (Garrubba, Turner, and Grieveson 2009), whilst in the United States up to 100,000 tracheotomies are performed annually (McCormick et al. 2015). Conditions requiring tracheostomies are diverse ranging from throat cancer to injury and, whilst the majority are of short duration, for some patients a tracheostomy becomes a permanent feature of their lives. The number of patients with permanent tracheostomies in New Zealand is unknown because patients are categorized by the primary medical condition, rather than by the insertion of a tracheostomy.

Often tracheostomies are performed as a matter of urgency and may occur without consultation with the patient (Kaub-Witteimer et al. 2003). The outcome of tracheostomy surgery is that a patient is left with a hole in the neck which is conspicuous by virtue of its location, involving a stoma through which protrudes a tube, along with a face plate and neck tapes to hold the tube in place. In New Zealand, different brands and types of tubes are available but silver, plastic or silicone tracheostomy tubes are provided to long-term adult users. Tracheostomy tubes can be fitted with a speaking valve that allows patients requiring mechanical assistance to speak more easily. Patients may have other ancillary equipment such as a humidifier valve (to reduce viscosity of mucus secretions) and a nebulizer (to deliver a mist that moisturizes the airways). Compounding the visual impact upon a tracheostomized individual's life is the care and time involved in management of the stoma and tracheostomy equipment. How often cleaning of the stoma, tube and ancillary equipment and tapes is necessary varies from person to person; whilst some people can manage with once or twice a day, for others it may be every few hours or more (NHS Trust 2010; Hess 2005). Consequently, patients are frequently unprepared for the impact on their daily life that tracheostomy surgery will make (Akenroye and Osukoya 2013; Gilony, Gilboa, and Blumstein 2005; Hashmi et al. 2013; Thompson and Kent 2001).

Individuals may also face a range of daily physical challenges, from adjusting to swallowing and speaking (Barnett 2006; Daudia and Gibbin 2006; Dawson 2014; Freeman-Sanderson et al. 2016; Morris et al. 2015), to dealing with the psychological aspects of their altered physical appearance. Some people use speaking valves which force the exhalation to pass through the vocal cords or, alternatively, speech can be produced by finger occlusion of the stoma. For some, the disfigurement caused by a tracheostomy can be distressing, and stigma from the response of others can be deeply hurtful (Bello, Di Muzio, and Antonelli 2016; Bronheim, Strain, and Biller 1991). There are also restrictions on a range of daily activities. Some individuals suffer a negative economic impact because the demands of care needs in relation to the patient's tracheostomy and underlying condition may influence their ability to maintain employment (Gul and Karadag 2010; Akenroye and Osukoya 2013).

Much of the existing tracheostomy literature is focused around surgical techniques and the clinical management of a tracheostomy and equipment

(Antonelli et al. 2005; Brigger and Hartnick 2009; Camacho et al. 2014; Daudia and Gibbin 2006; Dawson 2014; Dean 2014), particularly in acute settings within the hospital context. Previous studies have investigated specific aspects of tracheostomy experience in hospital settings or transitioning from hospital to home (Donnelly and Wiechula 2006; Foster 2010). A number of researchers have considered the psychosocial aspects of adults living with tracheostomies, including body image and social identity (Bronheim, Strain, and Biller 1991; Bule and Frings 2016; Clarke et al. 2014; Fingeret, Teo, and Goettsch 2015; Hashmi et al. 2013), or have investigated the experiences of parents of children with tracheostomies (Carnevale et al. 2006). There has been less attention paid to adult individuals' descriptions of living with a tracheostomy, despite the significant impact on their lives. A quantitative study by McCormick et al. (2015) examined life after a tracheostomy, in particular researching views on teaching patients and/or families how to care for a tracheostomy, and adjusting to the home environment. However, 90% of respondents in this study were parents of paediatric patients.

To date, there has been a lack of focus on life in the community for adults with a long-term tracheostomy. The current study aims to address that shortcoming by exploring and better understanding their experiences and needs in the broader social context. This study informed a wider co-design programme of research investigating how products can be designed to improve health care for individuals with long-term tracheostomies.

Methods

This exploratory qualitative study involved 10 long-term, adult tracheostomy users. The study was conducted between May and September 2016 and received ethical approval from *Auckland University of Technology's* ethics committee (approval number 16/166).

Recruitment and sampling

Participants were recruited through a major city hospital's Otorhinolaryngology database which included details of people who had received tracheostomies in the past, and which was accessed by hospital staff for the purposes of this study. The inclusion criteria were: English-speaking, their initial tracheostomy had occurred at least three months prior, and they were either resident within the Greater Auckland area to facilitate face-to-face interviews or were able to participate at a scheduled hospital appointment in Auckland. Initial contact was made by a hospital staff member who had been available for pre-ethics consultation and who provided eligible patients with a participant information sheet. Patients then contacted a member of the research team if they wished to take part in an interview.

Interviews

Interviews were either conducted in a private meeting room at a central city hospital (3), at the bedside of a hospitalized patient (1), in the participant's home (5) or in a retirement village (1). Interviews lasted from 45 minutes to an hour and a half and were audio recorded with the informed consent of the participants. Participants were able to bring a family member with them to also participate in the interview if they wished to do so or should they need a carer or family member to speak for them. With one exception, all participants indicated that they were happy to communicate via speech, even if this could be tiring for them, and none indicated the need for any other method of communication. Interviewers were careful to allow participants the time they needed to speak. The remaining participant chose to bring her adult daughter to speak on her behalf.

A brief questionnaire was developed to obtain demographic information including age, ethnicity, medical condition necessitating a tracheostomy and length of time since their original tracheostomy. Interview questions were developed after reviewing the tracheostomy literature and following consultations with members of the multi-disciplinary research team. The semi-structured interview guide was focused around two main elements: (1) the appropriateness of current tracheostomy design and potential design improvements; and (2) participants' experiences of living with a long-term tracheostomy. In this article, we report on the latter aspect.

Participants

Participants' ages ranged from 25 to over 65, and ethnicity included New Zealand-European (5), New Zealand-European/Maori (1), New Zealand-European/Maori/Samoan/Italian (1), British (1), Indian (1) and Tongan (1). Seven participants resided within major urban centres, whilst three lived in semi-rural areas. One participant who was interviewed at the hospital brought a family member who acted as her carer and also spoke for her due to speech difficulties. Demographic characteristics of the participants are shown in [Table 1](#).

Data analysis

Verbatim transcriptions were made of the audio recordings and participants were assigned numerical codes to retain anonymity. Thematic analysis was utilized to analyse the data (Braun and Clarke 2006) and data management and coding were aided by the use of NVivo software (version 11). Preliminary codes were developed by detailed attention to the transcripts and grouped into common ideas or patterns. Initial coding and analyses were undertaken by the first author, with discussion between all the authors contributing to shaping the final themes arising out of the data.

Table 1. Demographic characteristics of participants.

ID	Gender	Age range	Ethnicity	Reason for tracheostomy	Years since tracheostomy
1	Female	50–65	NZ European	Tumour	24
2	Male	50–65	NZ European	Heat stroke	38
3	Female	65+	NZ European	Polychondritis	20+
4	Female	30–34	Indian	Poisoning of oesophagus and windpipe	4
5	Female	65+	NZ European	Breathing difficulties – possibly asthma	14
6	Male	25–29	NZ European	Complications following heart surgery	3
7	Male	50–65	NZ European/Maori/ Samoan/Italian	Obstructive sleep apnoea	2
8	Female	65+	Tongan	Cancer	9
9	Female	65+	British	Respiratory inhibition	6 months
10	Female	30–34	NZ European/Maori	Complications following leg surgery	14 months

Results

The findings in this paper describe how individuals with long-term tracheostomies experience and manage their lives. Varied health conditions led to study participants requiring tracheostomies, including cancer, heat stroke, complications following surgery, poisoning and polychondritis (see Table 1). The length of time since participants had their original tracheostomy ranged from 6 months to 38 years. Although some participants had the opportunity to discuss before surgery whether or not they agreed to the insertion of the tracheostomy, for others, choice was not a factor and they awoke from an operation to find they had been tracheotomized.

Five main themes were derived from the data: ‘Acceptance’, ‘Restrictions of daily living’, ‘Devising own solutions’, ‘Reactions of others’ and ‘Advocating for oneself’.

Acceptance

Whilst acknowledging the necessity of having a tracheostomy to enable them to breathe, the degree of acceptance varied between interviewees, ranging from ambivalence tinged with regret, to emphatic dislike:

I did the pros and cons and there have been days when I wished I hadn’t, it would have been much easier.... (P5)

There’s a commitment [by me] to find ways of getting this trachy out which I hate with a vengeance. (P2)

Most individuals interviewed were not aware they would end up with a tracheostomy until after it was placed. Not having control over this decision, some interviewees rationalized their situation:

The reality is that without a tracheostomy I probably would be unable to breathe so it must have brought me relief. (P1)

... if I hadn't had that operation with that risk I wouldn't be here anyway so the trachy is a small price really to pay. (P2)

Despite the improbability of the majority of interviewees being able to ever have their tube removed, participants expressed this desire so that they could 'return to normal':

I was hoping it was going to be temporary but no, I still ask even now what the chances are. (P1)

This is just the last thing, if I can get this out then get on with my life. (P6)

Restrictions of daily living

Life with a tracheostomy was restricted, according to all participants, because daily care routines could be onerous and there were limitations on some of the activities interviewees had previously been able to do.

Care of the tracheostomy was a key topic amongst all participants because cleaning their tracheostomy tube and stoma were essential daily activities to prevent infection and to maintain the efficacy of their airway function. On leaving hospital, patients are generally discharged into the care of community nurses who, depending on the needs of the patient, will visit at regular intervals until the patient is confident of coping with their tracheostomy without assistance. Thereafter, ongoing contact with a community nurse may involve checking on the patient's condition or simply to replenish tubes or peripheral supplies. Patients with conditions that require ongoing hospital care may continue with hospital appointments which can entail tube replacement and provision of supplies. Once they had grasped the essentials of daily care, participants tended to prefer to clean their tubes themselves, without the involvement of either hospital or community nurses.

A tracheostomy tube consists of an outer tube, an inner cannula and an introducer. The inner cannula can be removed for ease of cleaning, leaving the outer tube in place; nevertheless, the stoma requires cleaning, as does the face plate which holds the tapes in place to secure the tube. The extent of cleaning required often depended on the individual's causal condition and the amount of mucus produced. Clothing could become soiled, should mucus production be excessive. Tracheostomy equipment, such as spare tubes, together with cleaning items needed to be carried everywhere they went, in case of emergency.

When I go out on a Wednesday to do my shopping I take a roll of this, I take what I call my mascara brush [the special brush provided] for cleaning out my tubes, I take a plastic bag and I have to take a clean top because it can be that violent [expelling mucus] that sometimes I just don't have time to get my tissue out before it actually blows. (P7)

Care could be undertaken by a family member. One daughter cared for her mother and attended to the daily cleaning of her tracheostomy tube:

... it's become as a life for me to do this as a job for her. (P8)

It was not only cleaning that restricted participants' lives; there were various other constraints although the extent of these depended, in part, on the medical condition that had led to tracheostomy surgery. Even simple tasks, such as having a shower, required more care and adaptation due to the danger of water entering the tracheostomy tube:

I have the [shower] rose a bit lower ... because my neck, the tumours on there, I can't hyper extend so I can't actually tip my head too far back to wash it, ... the soap can just all go straight to your lungs and you can drown yourself in a couple of splashes of water. (P1)

Speech can become compromised following tracheostomy surgery. Initially, patients have to re-learn how to use the necessary muscles to be able to speak and may be without a voice during the interim period, whilst later the voice may not be as strong as it was previously:

... we had to get an answerphone on and if my Mum phoned I said to my boys "tell Nana that I will bang one for yes and two for no but she's got to ask me questions because I can't talk to her" so that's what we used to do. (P3)

Well the main one would be going out into big crowds because the voice quality is not there ... so if I go out to a bar with friends I do it very seldomly because I have to try and yell and people can't hear me so they have to get real close to hear me ... (P6)

Driving a car presented problems for some participants, particularly if they were prone to coughing fits, which a small number of our interviewees suffered. Thus, individuals are restricted in their choice of modes of transport and may have to rely on friends or family members:

Um, driving I usually get my landlord who lives up there or one of my friends to take me because if I have a coughing fit behind the wheel I could pass out. (P7)

Tasks like cooking were made more difficult for a number of participants, especially if they did not, or could not, use a speaking valve and had to rely on placing a finger over the tracheostomy stoma to create a voice, whilst simple activities such as reading a book could also be problematic due to the placement of the head and neck when looking down to read, causing discomfort:

You see I need to hold this [the stoma] to talk so every time one hand is always busy so whenever I cook (P4)

I used to be able to lie in bed with a book, I can't do that now. (P7)

Participation in social and community activities was restricted, whilst leisure pursuits, in particular swimming and underwater sports, were no longer possible due to the likelihood of drowning:

Probably I didn't go out a lot as well because of it, it stuffed up my social life big time. (P1)

Like now I am going to church but I am still not baptised so obviously I can't get baptised because of this. (P4)

Swimming of course, water, anything water related. I used to scuba dive when I was about 25 until I had my trachy and I haven't put my head under water since (P2)

Although some participants of employment age were able to continue working after surgery, adjustments had to be made, depending on their environment:

When I get out and doing practical things out in the factory, if it's a bit dusty then it's not ideal then because, especially if the humidifier is on I end up breathing in some dust and you get it down and you are coughing everywhere (P6)

Returning to a previous job, however, was not always practicable, despite a desire to earn a living, and one participant became self-employed rather than live on a benefit:

... I was a sales rep ... and they held my job open for me but I ended up in and out of hospital every 3 months so I just said let it go. Then when I felt I was ready to start work I put my CV out there, got the interviews but as soon as they met me I didn't get the job because of the trachy. I got to the stage where I thought f*** everybody and I started my own business up and it's still going 17 years down the track. (P1)

Five interviewees were of retirement age. For three younger participants, though, employment was no longer feasible due in part to their principal health condition. As a result, income dropped substantially and expenses rose due to health-related costs:

... I don't have any money to spare being on the benefit. Before I got sick I was on 68K a year and to go from that down to what? \$380 - \$400 a week its aaarrgghh and \$250 of that for rent, then medications because I'm not only dealing with this... . (P7)

Devising own solutions

Participants were innovative in meeting any challenges arising out of tracheostomy use by devising their own solutions. When patients are supplied with a tracheostomy kit, they are also supplied with neck tapes that secure the tracheostomy tube in place. The medicalized appearance of the neck ties, which are white and clearly obvious, means some people prefer to find an alternative, that does not draw attention to themselves. One participant overcame this by dyeing hers a skin tone. Tapes also get dirty very quickly and wear out; obtaining replacement tapes is often at the patient's cost. A number of participants had created novel solutions to overcome this dilemma:

They [tracheostomy tubes] come with one [neck tape] each and no one seems to be able to get any more so I just invent them. I've found that the elastic in old bras is quite useful and a bit of velcro. (P5)

I had these chains ... and I thought instead of having that cloth thing round there tying it up, it gets filthy all the time, why don't I get one of these chains.... I got

them to leave more links in it so that because when you get inflammation and it swells this can dig in so as long as I get them to leave the links in and then I can move it along to where I need it to go to without digging into your throat. (P3)

Participants had to rely on their own initiative in the case of the unexpected happening:

A couple of times, these [cleaning brushes] have a habit of breaking off inside. the first time it broke off I was in the bathroom and I pulled it out ... got the end off and put some Vaseline down the tube and forced it back in. (P7)

Although patients are taught in hospital how to manage their tracheostomy tube and keep them sterile, once in the home other more practical methods have to be found for use on a daily basis.

I stick them [the neck ties] in the wash with tea towels and bleach and soap powder on a 2-hour wash and soak so they get a fair hammering and the tubes I find I just use dish-washing liquid and hot water and soak them and clean them out with a brush and use cotton buds to dry them out. (P5)

Reactions of others

Coping mechanisms had to extend beyond accepting and caring for tracheostomies, participants also had to cope with the reactions of others. Individuals' views and perceptions varied as to how concerned they were regarding the visibility of their tracheostomy tube. Wearing scarves could be a practical option, particularly in winter, but care had to be taken not to inhale the fibres. Some participants tried to be impervious to the reactions of others but a number of interviewees did feel stigmatized:

I kind of think if you don't want to know me while I've got a trachy, well I don't want to know you either. (P10)

I'm going away next weekend with a friend ... I said to her "just be prepared, people stare, don't worry about it, they're not staring at you." (P1)

One participant, though, felt advantage was to be gained from people's reactions:

I welcome it. I've got this so I might as well use it, might as well have a bit of fun. I could sit here and go woe is me, the world owes me, why did it happen? (P7)

Another interviewee considered the possibility that he was interpreting other people's reactions as being negative when it may not have been the case:

I mean obviously people do look, you can tell they're looking but most people probably think 'oh yeah he's got a trachy' but in your mind's eye sometimes I think there's a negative thought that they're thinking less of me but they probably aren't. (P6)

Advocating for oneself

People with tracheostomies are categorized by their original illness but can be defined by their tracheostomy as that is a visible aspect of their condition. Because of the lack of commonality, patients find they are alone in coping with life with a tracheostomy. When asked if participants were aware of others like them, the result was negative:

I've never sat down and had a conversation with someone in the same position as me. (P1)

No, I really don't know anyone. (P4)

Support groups can bring together people facing similar medical issues, offering the opportunity to share experiences and advice. It can be helpful for people just being able to talk with others who are in the same situation. Despite the myriad of support organizations within New Zealand, there is no tracheostomy group in existence. Support groups can also offer advocacy in matters that affect members. Advocacy was an issue that some participants felt was essential, not only for themselves but also for others less able or less confident in speaking up:

I'm fairly hot on the topic because I've got a voice and I can speak, a lot of the people that are dealing with a tracheostomy in the community have trouble communicating, are older, less confident, minorities, language issues. How the hell they survive quite frankly I've got no idea. (P2)

A few weeks ago, I was back there [in the ward], they're up to it now but I had to yell and scream to get anything done. If I hadn't, the other patients would have had to go through the same procedures that I did. (P7)

Aware of newly tracheostomized patients' need for information and reassurance, participants were more than willing to share their knowledge and experiences and help others, should they be asked, although their offers were seldom accepted:

In hospital I bumped into a couple and it's been hard for them because they're new but good for them because I come along and I'm talking like this and they're like oh ... it's not that bad after all. (P1)

I know that at one stage they were asking me ... would I like to come in and talk to the tracheostomy new people and I said not a problem, just yell out, but they never did. (P3)

Discussion

This study provides unique insights into how individuals with permanent tracheostomies survive in the community, and contributes to what is currently very limited international literature on this topic. It was an exploratory study and consequently the number of participants was small. Nonetheless, the participants provided in-depth depictions of life with a tracheostomy, the difficulties they

faced on a daily basis and the solutions they conceived, together with the coping mechanisms they adopted to overcome hurdles. Interviewees came from a range of ethnic and socio-economic backgrounds, yet there was a consensus on many issues faced by each participant. People with permanent tracheostomies are to be found worldwide and, whilst this research was undertaken in New Zealand, there is every likelihood that the challenges faced by individuals in New Zealand will be similar to those faced elsewhere.

Caring for themselves, their tracheostomy equipment and coping with major changes to their lives including, in some cases, the ability to work, limitations to social and active life as well as the psychosocial aspects of their new selves, make demands on all tracheostomized individuals. Whilst all participants have a continuing relationship with both tertiary and primary health care providers to varying degrees, nevertheless, they do face many challenges in isolation from professional care.

The time since interviewees were tracheostomized varied from a few months to several decades. Acceptance was made more bearable because participants valued the fact that, by having the tracheostomy, they were alive and able to breathe, as supported by Narayanaswami et al.(2000). Nevertheless, interviewees gave no indication that they saw their tracheostomy as integral to themselves as a person; instead they had a desire to return to life without a tracheostomy and to do the types of activities they had previously enjoyed. As Foster (2010) notes, regaining control over the things that are important to people helps achieve a sense of normality.

Tracheostomies can require significant care and maintenance to prevent problems occurring (NHS Trust 2010; Capital & Coast District Health Board 2015). In the community, individuals have to manage this care themselves, which is a substantial daily commitment impacting on their freedom to live a normal life. The discussion on care and associated lifestyle restrictions accounted for a significant proportion of the interview time of each participant, evidencing the degree to which this affected them.

Difficulty in speaking can inhibit social interactions and isolate patients (Freeman-Sanderson et al. 2011; Danker et al. 2010). Regaining that ability to speak is of particular importance to recovering tracheostomy patients (Fingeret, Teo, and Goettsch 2015; Freeman-Sanderson et al. 2011; Laakso et al. 2011). In this study, all but one of the participants had the facility of speech but found their voices were not as strong as earlier, thereby hampering social interactions, particularly in noisy environments.

Employment provides a number of benefits. Although monetary remuneration is essential for material wellbeing, work also meets important psychosocial needs of individuals, in addition to providing a social role and social status (Waddell and Burton 2006). There is also strong evidence that, for people with health conditions or disabilities, employment can lead to better health outcomes (Aylward et al. 2010; Black 2008). However, employment is not always possible with

a time-consuming medical regime. Three participants were unemployed because of the difficulty in holding down a job and coping with the vicissitudes of life due to their persisting health problems, regular hospital admissions and contending with the unsociable aspects of tracheostomy consequences.

Other lifestyle restrictions related to activities which many people take for granted, such as driving a vehicle, or reading a book.

Interviewees exhibited great resourcefulness, creativity and competence in addressing daily practical needs together with innovations in equipment adaption. They illustrated occasions where equipment needs, such as sufficient supplies of neck tapes free of charge, which soiled and wore out easily, were not always met. Other equipment was not always satisfactory for the task in hand due to breakages. Patient guidelines on home care of equipment specify certain procedures to be followed (NHS Trust 2010; Capital & Coast District Health Board 2015). However, our interviewees had to take a practical stance from both an economic and a time perspective. Whilst resourcefulness can indicate the ability to deal with challenging situations and leads to a better quality of life and increased life satisfaction (Zauszniewski and Bekhet 2011), nevertheless, some of these challenges simply revolve around supply needs and highlight the necessity of meeting those basic requirements.

People who look different can attract unfavourable reactions from others; for example, staring, unwanted questions, ridicule and avoidance (Robinson, Ramsey, and Partridge 1996). This can lead to social avoidance and a reluctance to participate in social activities. Some participants in this study had learnt to deal with negative reactions but others avoided activities such as attending church and other community events. Avoidance of activities can lead to social withdrawal which has its own health implications (Rumsey, Clarke, and White 2003).

Despite the length of time since some study participants had been tracheostomized, none of the interviewees were aware of any other long-term user with whom they could share experiences and information, which was considered highly important among study participants. Previous studies have identified support groups as a valuable coping mechanism (Bule and Frings 2016), as well as contributing to the successful reintegration of patients into the community (Dooks et al. 2012). Compared to many other health conditions within New Zealand, the lack of a dedicated support group was surprising. Support groups exist in New Zealand for a wide range of health conditions from the physical to mental health. Overseas, neck breathers support groups exist to raise awareness about tracheostomy patients and to give them a voice (Royal Liverpool & Broadgreen University Hospital NHS Trust 2016). Veterans of tracheostomies in our study were keen to help newly tracheostomized patients by sharing their experiences, solutions and by offering support. That they had no vehicle by which to proffer their assistance or to take

advantage of support themselves illustrates the need for such an organization within New Zealand.

Conclusions

This study has provided a rare space for individuals with permanent tracheostomies to speak, by providing a forum in which they were empowered to share their often solitary experiences. Whilst health care providers afford the facility for those people with restricted airways problems to be able to breathe and lead a functioning life, individuals restricted to living with permanent tracheostomies daily face a range of obstacles which require ingenuity, determination, strength of will and purpose to live that life. In capturing the opinions of a diverse group of long-term tracheostomized individuals, it is clear that changes could be made to improve quality of life.

Although some issues such as employment are not easy to resolve, solutions can be more readily found for others. A support group, for instance, could be formed through the auspices of a hospital, where the provision of a safe meeting environment might be made available, enabling participants to feel at ease amongst people with a similar condition. Alternatively, in this age of social media, an online nationwide network might be set up offering a forum for support, advocacy, information and resources either through the auspices of a tertiary care provider, or a group of like-minded people.

Enhancements to the design of tracheostomy products may well contribute to an improved quality of life for long-term tracheostomy patients. This study draws attention to the challenges faced by designers of health care products when considering a neglected group of users. Those suffering long-term, minority conditions are very alienated compared to populations of more widespread conditions, such as cancer, diabetes and heart disease. Designers have an incredible opportunity to act on behalf of and work with these minority groups, creating products that may improve life markedly particularly with regard to functional activities such as bathing or swimming.

This under-researched and largely untold topic was succinctly summed up by one study participant:

I'm afraid you've got a tiger by the tail and I'm happy to help you swing it. (P2)

Disclosure statement

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Notes on contributors

Jill Wrapson is a researcher with a background in the social history of medicine, and a particular interest in contemporary health. Recent research has revolved around user experiences in a children's hospital outpatients' environment, as well as investigating the challenges people face living with long-term tracheostomies. Jill is currently involved in a person-centred project exploring the most effective ways to increase the impact of academic health research.


Niamh Patterson is a recent BSc (Hons) psychology graduate who has worked as a research assistant with the Psychophysiology Lab at Auckland University of Technology, as well as with the AUT's Design for Health and Wellbeing Lab. Her research with the DHW Lab has focused primarily on patient psychosocial wellbeing.


Ivana Nakarada-Kordic is a qualitative researcher with a background in human factors and health psychology. Her work at the DHW Lab focuses on user experiences in the health care context. As part of the Lab's multidisciplinary team, she is currently involved in various co-design projects involving patients, designers, researchers and clinicians in the Auckland area.

Stephen Reay is co-director of the Design for Health and Wellbeing Lab, a collaboration between the Auckland District Health Board and AUT, initiated to develop an intentional relationship between design process and the area of health and wellbeing, and underpinned by interdisciplinary collaboration and a strong focus on user-centred design.

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