

**USING INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS TO  
STUDY PATIENT AND FAMILY MEMBERS' EXPERIENCES OF A  
MECHANICAL VENTILATION WEANING UNIT**

Craig D. Murray, Jo Jury, Victoria Molyneaux,  
Jane Simpson & David J. Wilde

For publication in: Hayre, C.M. and Muller, D. (eds.) *Enhancing Healthcare and  
Rehabilitation: The Impact of Qualitative Research*. CRC Press

**USING INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS TO  
STUDY PATIENT AND FAMILY MEMBERS' EXPERIENCES OF A  
MECHANICAL VENTILATION WEANING UNIT**

**ABSTRACT**

This chapter sets out the use of interpretative phenomenological analysis to study lived experiences in healthcare and rehabilitation settings. The study focus is on patient and family members' experiences of a mechanical ventilation weaning unit. The analysis highlighted participants' perception of both themselves and the unit being different and special in a number of ways, particularly because the unit has the ability to choose who comes onto it, along with the difficulties surrounding the transition from unit to home. The process of transitioning from the unit back to home life was experienced as a difficult one as there were a range of barriers which impeded the discharge process. Although the present findings offer particular issues of consideration for specialist mechanical ventilation weaning units and ICUs, our description and application of IPA here serves an illustrative purpose for others interested in applying qualitative methods for similar purposes to other healthcare settings.

Key words: healthcare; interpretative phenomenological analysis; mechanical ventilation; qualitative; rehabilitation; weaning

**USING INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS TO  
STUDY PATIENT AND FAMILY MEMBERS' EXPERIENCES OF A  
MECHANICAL VENTILATION WEANING UNIT**

**INTRODUCTION**

In this chapter we set out a phenomenological approach to collecting and analysing qualitative data (that of interpretative phenomenological analysis, or IPA) and apply this in a study of patient and family members' experiences of a mechanical ventilation weaning unit. We then consider how the findings of this study may inform healthcare and rehabilitation for this patient group. Our description and application of IPA here serves an illustrative purpose for others interested in applying qualitative methods for similar purposes to other healthcare settings.

**INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS (IPA)**

IPA was developed by Jonathan Smith (Smith, 2004, 2011; Smith & Osborn, 2008; Smith, Jarman & Osborn, 1999; Smith, Flowers & Larkin, 2009) with the vision to return the study of 'lived experience' to the centre ground of psychology research attention by cultivating a phenomenology-based methodology that was inherently psychological in nature. IPA treats language as disclosing participants' being-in-the-world, and the meanings of this for them. It is an approach intended to explore how participants experience their world, and hence enable an insider's perspective of the topic under study.

IPA is principally phenomenological owing to the central importance it accords to the lived experience of a particular phenomenon as it is perceived and understood by the person concerned. The approach aims to capture the complexity inherent in individual experience

and make transparent the person's sense making of that experience. Consequently, there is no attempt in the presentation of the findings to produce objective statements of 'truth' about a phenomenon. Instead, an interpretative account is produced, comprised of detailed expositions of participants' understandings and meanings, and drawing out the psychological entailments of these.

IPA acknowledges that achieving an understanding another's lifeworld is a delicate and collaborative social enterprise between participant and researcher; as Smith, Jarman and Osborn (1999) note, access to a participant's lifeworld, "...depends on and is complicated by the researcher's own conceptions...required in order to make sense of that other personal world through a process of interpretative activity" (pp. 218-219). Smith (2011) refers to this process of the researcher trying to make sense of the participant trying to make sense of their experience as a 'double hermeneutic'.

In order to foreground the distinctive nature of personal experience, IPA takes an idiographic approach to research (Smith, 2011) involving the painstaking, fine-grained analysis of individual cases, and seeking to illuminate the meaning and sense-making of lived phenomena as divulged within personal narratives. Because of this, IPA studies may focus on single case studies, where the commitment to idiography is most evident in the detailed reporting of one person's experience. However, it more common for IPA studies to involve a small numbers of participants, where concerns centre around "...the balance of convergence and divergence within the sample, not only presenting both shared themes but also [...] the particular way in which these themes play out for individuals" (Smith, 2011, p. 10).

As already discussed, IPA is primarily a phenomenological methodology with an acute emphasis on the psychological study of lived experience and how people make sense of their experiences. Nonetheless, it also has links with more mainstream psychology in that it recognises that inherent in the sense-making process there is a "...chain of connection

between people's talk and their thinking and emotional state" (Smith & Osborn, p. 54). However, as one might expect when carrying out psychological research, this 'chain of connection' is not straightforward – people often find it difficult to say what they mean, finding it challenging to put into words complex feelings and thoughts. Accordingly, it is incumbent on the researcher to draw out and interpret what people are thinking and feeling from the data obtained. When engaging in this kind of interpretative activity, IPA acknowledges that it is impossible to 'get into the head' of another human being and know their thoughts directly. Instead, the IPA researcher tries to develop a critically formed viewpoint from which they can then try to understand what it is like to have a given experience.

Given the close attention to detail and the intense idiographic nature of the approach taken, IPA research necessitates the purposive recruitment of a small sample of people who share a common experience and possibly other characteristics as well. Consequently, IPA studies are typically conducted with small samples of 4-10 participants that form a homogenous sample. Homogeneity can occur on a variety of levels. At the most fundamental level, participants in an IPA study are homogenous because they share an experience of a similar phenomenon. Other levels of homogeneity can apply to a given sample; however, these parameters will vary according to the particular research question and topic area (Smith, 2004). The analysis itself will pay concerted attention to the thorough examination of each participant case in turn until a point is reached where "...some degree of closure or gestalt has been achieved" (Smith, 2004, p. 41) for each individual. Only then will the researcher consider a cross-case analysis with a view to teasing out the convergences and divergences available within the data.

In terms of output, the proof of the idiographic focus of the analysis should be evident in the writing up of the findings. A detailed, nuanced and resonant account of the

participants' lifeworlds and meaning-making of their experiences of a given phenomenon should be presented. Smith (2004) notes that a good quality IPA write up should aim to strike a balance between addressing the common elements that participants as a sample experienced, whilst retaining the uniqueness of each participant in such experiences.

As IPA has grown in stature and popularity, a variety of methods have been used to collect the experientially rich data necessary to perform a suitable analysis: for example, data have been culled from naturally occurring data sources existing on the Internet such as web discussion/message forums (Mulveen & Hepworth, 2006); through email interviews (Murray & Rhodes, 2005); diaries (Boserman, 2009); and focus groups (Palmer, Larkin, de Visser & Fadden, 2010). However, the most popular and utilised method of data collection in the vast majority of IPA studies remains the semi-structured interview.

## **MECHANICAL VENTILATION AND WEANING**

The study reported here used interpretative phenomenological analysis to examine experiences of a mechanical ventilation unit. Mechanical ventilation (MV) is used when a person is unable to breathe unaided, usually as a result of chronic illness such as heart failure (Ayalon, 2007). Machinery delivers air to a person's lungs, either invasively through a tracheostomy, or non-invasively, for example via a sealed mask. The experience of MV can be a short one; for most people removal of the ventilator causes little distress or difficulty and is a quick process (Boles et al, 2007). However, up to 10% of users can become physically or psychologically dependent on MV and therefore have to be weaned from the equipment (Wise et al., 2011).

Weaning can be difficult and complex (Henneman et al., 2002). Dependency can be seen for a number of reasons, including lung disease, cardiac impairment, or psychosocial and psychological factors (Arslanian-Engoren & Scott, 2003; Cook, Meade & Perry, 2001;

NHS Modernisation Agency, 2002; Wunderlich, Perry, Lavin & Katz, 1999). Greater understanding of the emotions that people experience during MV and the weaning process has been derived from qualitative studies. In a systematic review of five qualitative studies (Jablonski, 1994; Jenny & Logan, 1996; Logan & Jenny, 1997; Mendel & Khan, 1980; Wunderlich et al., 1999), Cook et al. (2001) highlighted the need to consider the emotions of the person being weaned. They argued that the weaning process evoked feelings of frustration, hopelessness and fear.

Due to the range of difficulties and complications seen in weaning, it is important to have a specialist multi-disciplinary team (MDT) around the person being weaned (Henneman et al., 2002; Hoffman, Tasota, Zullo, Scharfenberg & Donahoe, 2005). Specialist units can be more financially viable than weaning on the ICU (e.g., Seneff, Wagner, Thompson, Honeycutt & Silver, 2000). The study described in this chapter is set within a specialist weaning unit in the United Kingdom. The unit is made up of an MDT which includes respiratory physicians with a special interest in weaning, nurses, physiotherapists, occupational therapists and psychologists.

Whereas previous research has highlighted the importance of psychological and psychosocial aspects of MV and weaning, there is an absence of research on experiences of a weaning unit taken from a psychological perspective. IPA, with its focus on lived experience, meaning-making and psychology, provides an appropriate, rigorous methodological approach to study this topic. In addition, given the central role that family members play in patients' recovery – be it within the hospital whilst the inpatient is sedated (Dreyer & Nortvedt, 2008), during the transition from hospital to home (Mustfa et al., 2006), or caring for the person at home (Huang & Peng, 2010) - it is important to gain insight into their experiences also (Happ et al., 2007).

Given the above considerations, the study presented here aimed to gain a better understanding of the experience of former patients and their family members who became involved with a mechanical ventilation weaning unit. By interviewing discharged patients and their significant others, the study aimed to develop healthcare professionals' understanding of the lived experiences of these people as well as the psychological impact of being involved with the unit.

## **STUDY SETTING**

The specialist weaning unit that is the focus of the current research was set up in the United Kingdom and opened in early 2010. It was one of only two in the country at the time of opening and provides specialist weaning care within a hospital setting. The unit itself consists of four dedicated weaning beds within a ventilation ward. A multidisciplinary team (MDT), which includes respiratory physicians with a special interest in weaning, nurses, physiotherapists, occupational therapists and psychologists, staffs the unit.

This study aimed to gain a better understanding of the experience of former patients and their significant others who become involved with the mechanical ventilation weaning unit. By interviewing people who had been discharged and their significant others, it aimed to develop healthcare professionals' understanding of the lived experiences of these people as well as the psychological impact of being involved with the unit. It was a timely piece of work because at the time of data collection, the weaning unit had just completed its second year of operation and therefore the research aimed to guide developing practices and procedures. It was also intended to be of benefit to other units already in operation, or looking to open up in the future. Additionally, the study could provide clinical implications for those who carry out weaning within an ICU or similar setting as it might guide the support provided to people who spend time there.



## **DATA COLLECTION AND ANALYSIS**

### **Sampling and Participants**

This study was approved by a National Health Service (NHS) Research Ethics Committee and the weaning unit's NHS Research and Development office. All participants gave informed consent to be interviewed and permission for their data to be used in this study. The Ventilation Business Manager (VBM) identified 21 people who had undergone weaning at the unit, of which four were still inpatients. Of the 17 discharged patients, five had died, or judged close to death by the VBM. This left 12 people who were invited to take part in this study. As part of this invitation, patients were asked to identify a family member or a friend who had spent time with them on the unit who might also wish to take part. All potential participants were asked to express their interest to the research team directly either by email, post or telephone. As a result, seven people took part: three patients and their partners, and an additional family member (mother) of a patient who did not take part (see Table 1). Thus, the sample size and composition comprised a small and relatively homogenous group, as appropriate for IPA.

[INSERT TABLE 1 ABOUT HERE]

### **Interview Procedure**

Semi-structured interviews were conducted and audio recorded in participants' homes, with interviews lasting between 33 and 70 minutes each. The interview schedule was developed by the research team, including the MDT within the weaning unit, and was designed to let participants recount their experiences with as little direction as possible (see Table 2).

Example questions included 'How did you feel when moved there (the weaning unit)?' and (in relation to discharge) 'how was planning this managed?'

[INSERT TABLE 2 ABOUT HERE]

## **Data Analysis**

There are many guides available on how to conduct IPA, discussing different levels of analysis that may be attempted (Smith et al., 2009), and different ways of presenting IPA findings. IPA is an epistemological and methodological approach that can tolerate some variation in procedures and presentation (Smith & Osborn, 2008). For example, we focus our own description of analysis here on identifying themes within and across transcripts.

To begin with, transcripts were read a number of times to increase the researcher's level of familiarity with the data. Each transcript was read to identify themes from a psychological perspective. Notations were made on parts of the text of relevance to the central research focus (patients' and their family members' experiences of the mechanical ventilation weaning unit). This included summarizing material, making connections between passages and statements, and providing preliminary interpretations. Following this, the fundamental substance of the text was recorded in the form of key words and phrases that captured the essence of these emergent themes. These keywords served as early placing or interpretative reflections on what was thought to be present in the text. Analyzing each transcript individually allowed the researchers to be open to new themes from each participant, rather than being driven by themes from previous transcripts. Once this process was completed for each transcript a list of the emergent themes was collated so that connections across the transcripts could be examined. Patterns across participants were then explored, including commonalities and nuances within and between participants' data. Related themes were grouped together and the final theme titling modified to reflect the depth and breadth within and across accounts. This stage of analysis focused on producing a

parsimonious and saturated account of the study data that resulted in a three-theme narrative structure: being different; the unit as both a community and a lonely place; and the transition from unit to home. Each of these themes is presented below and illustrated using data excerpts from the interviews conducted.

## **FINDINGS**

### **Being Different**

The weaning unit gave participants the opportunity to feel special or different in some way. This unit is not a typical hospital ward, and therefore does not operate in the same way that more traditional wards might have to, where people are typically admitted not based on choice but based on physical need. Participants understood that the weaning unit actively selected people who might benefit from the service it offered and tried to make sense of this:

They felt that I was a suitable candidate to go to the Unit. They wanted to try the system on me and wean me off ventilation...They thought they could do something, there's no point in making someone who wasn't going to do any good. I must have been fighting the good fight and not giving up. (Alan)

Alan made sense of this decision as being about the personality of the individual, rather than being based on a medical decision. To be chosen meant that the individual was actively behaving in a particular way and this will cause them to have a good weaning outcome, something that would be wasted on a person who was not going to be able to make the most of the opportunity. Therefore, the responsibility for the success or failure of weaning is partly put onto the individual rather than the medics, although some of this responsibility

does stay with the staff, who will be able to 'do something'. Alan recognised himself that he was 'fighting the good fight', therefore making him stand out from others who might not be putting as much effort into recovering. This sense of feeling unique was also discussed by Helen, who described how her husband, Dan, was seen as someone special to the weaning unit doctors:

Cardiology had been, you know monitoring him closely, and they probably wanted him to go onto the cardio ward, but they weren't sure, are you with me, I think Dr [name omitted] had sort of like decided that wasn't happening, and he was going his way. He wanted him as sort of like a, a prodigy. (Helen)

Dan was seen as being special, and this resulted in a battle between different specialities within the hospital, where Dan was wanted by both teams. However, although the doctors might make the decision that someone is suitable to go onto the unit, the decision remains a joint one, and people are given the option whether to accept or decline a place. In the following extract, Eddie is talking about his partner, a former patient on the unit:

They offered us the option of going to the Unit. And Dr [name omitted] came, we said, Fiona said yes, and Dr [name omitted] came down to assess her, and was very glad to accept her as a patient, with the objective of weaning her off the tracheostomy. (Eddie)

This decision can be one that is made by both the person admitted to the unit and the significant other, however is ultimately up to the individual who is to be admitted. Whilst there was a sense that this is a joint decision, it is actually the person admitted to the unit who is in control of saying yes or no. This was something that was conveyed by all participants

except Carol – mother of a former patient - who showed that control is not always something that the person admitted to the unit or the significant other can keep:

So he did stay there on that ward [another ward in hospital] and then he had, he had a respiratory arrest. Which then, he needed resuscitation really, which then forced the move down to the [weaning] Unit. So although we were relieved that he was going, it wasn't quite as straightforward as that, you know. It was more difficult. But when he actually went down there, it was very clear that he needed to be somewhere other than a ward. (Carol)

These extracts show how the weaning unit was seen as somewhere different and, whether they have control over the decision or not, being moved to the unit can bring positive emotions and make a person feel special in some way.

### **The unit as both a community and a lonely place**

The unit was discussed as a special place throughout the interviews, and this was expressed most clearly by the idea of the unit being like a community. It was portrayed as different in this aspect to other hospital settings, despite being within a hospital setting:

... being in the hospital, little more of a community feeling than a big block of wards. Although having, because I wasn't in a ward, luckily that felt a little bit special too in a way...Didn't think of it being as a, a general ward. (Fiona)

By thinking of the unit as being unlike a general ward, the idea of feeling special was maintained, and removed from the hospital setting in which it was surrounded. This sense of

community led Fiona to feel a bond with the other people on the unit, who were going through similar experiences:

We all became, you know, not friends as such but we got to know each other, have a laugh about each other's' masks and stuff, and helped each other as we got stronger, to go to the loo and stuff. (Fiona)

This bond meant that emotional support could be offered, sometimes through the more practical care that staff would otherwise provide. There was a sense of the people on the unit getting better together, and this instilled a sense of group cohesion. However, Fiona made the clear distinction between this bond and friendship; these people are not close to her, but rather a temporary support structure that will give and take help where needed.

As continuing support was often needed participants still felt part of the unit. Several participants spoke about revisiting the unit once they had been discharged, and two spoke about going back to give gifts of appreciation. Hence the sense of community and support continued even after people left the unit:

People were coming and visiting...who had been in...they'd just come visiting and say, I need a mask or, I need a whatever or, breathing was a bit out last night, and they'd either say to them I'll get you a mask or, let's have a, we'll keep you overnight and have a look you know. I just thought that was amazing. (Helen)

The unit was perceived as a calm, supportive, and 'good' place to be:

I actually feel very comfortable going there cos you know there's such a good, such a good place. You feel good. (Eddie)

Conversely, there were times when this sense of community and support dissipated. The term 'lonely' was used a lot throughout the data set and encapsulated a time for those on the unit when significant others were not around:

I realised it was lonely. And also in a small, in a room on your own like that. ...I found I couldn't concentrate. (Alan)

Alan's sense of isolation and loneliness was also recognised by his partner, Bernice: He was lonely...And when he was getting a lot of constant care, it was ok because there was somebody there, but when he was getting better, there wasn't anybody there and he would have to ring for attention if he needed it you know, and he was lonely then. (Bernice)

### **The transition from unit to home**

Contrary to the experience of having choice to move to the unit, leaving was something that was out of participants' control, and at times fraught with battles, leaving participants unsure about when they or their loved one could leave:

Then they said, "Well if everything's ok, you can go home Thursday". ... And then I would think, oh great, Thursday. Thursday night, guaranteed, the physiotherapist would be on because I've not been able to get my breath. So another week, and then eventually, they said, I could go home...I got out of there. (Fiona)

Therefore, for some people on the unit, a discharge date could be given tentatively, however as the person's physical status could vary, this might change, meaning that people had to wait to be re-assessed. Fiona described the delay as being due to her physical condition, as she was not able to get her breath and it remained something outside of her control. Being out of control was something that other participants felt, none more so than Carol, who described having a difficult battle to get her son discharged from the unit.

When somebody needs to come out to the community with a tracheostomy and, use of the ventilator and other pieces of equipment, it's a very long process. It's just a very difficult time so we just, we were just playing a kind of waiting game. (Carol)

Carol's son had not been weaned from his tracheostomy, and this along with other complicated health difficulties meant that discharge was not as simple as getting oxygen levels to an acceptable standard. For Carol, this was a battle she had to fight, and she found that they were waiting, not because of the unit, but because of other agencies that needed to be co-ordinated: "I think the Unit staff are, it, it's out of their hands." (Carol). Processes like this could be difficult for the significant other as they are keen to have their loved one back home and therefore they can experience the same frustration as the person who has been admitted.

There was a sense of hope in recognising that that people did find their way out of the weaning unit, and progress towards this could be seen by moving from a tracheostomy to non-invasive ventilation. Similarly to other participants, Eddie portrayed the discharge process as having delays and 'diversions', but these were minimised as the hope for an exit was placed as paramount importance. All participants spoke about the transition to getting home, and although adjusting to life after the unit was seen as difficult, only one participant described the difficult emotions he felt over leaving the unit:



... there was a fear of coming home, you know because I'd been there and maybe, maybe because I was in a comfort zone, and you knew if anything went wrong they were there you know, and I was coming home here and I'd have to get up the stairs and, stuff like that you know. (Dan).

Dan became safe at the unit and did not need to think about the care he would receive. There was a fear that something would go wrong at home, although this was related to practical issues rather than worries about his breathing. This worry was not limited to people who had been admitted, and Carol, a significant other, was also worried about the practicalities of managing without staff:

So we were then forced to be there, cos if we'd have brought him home, it would have been very tricky cos one of us would have been up all night with him. (Carol)

Here Carol describes feeling as though she had no choice but to remain in the unit, and although she was fighting for her son to return home, she was aware of the difficulties this transition would bring. Carol had the distinction that her son had not been weaned, unlike all the other people who had been on the unit. This placed a pressure on her to continue the level of care that would have been available when on the unit.

Although difficulties with the transition from the unit to home were recounted, one participant summed up the feeling of eventually returning home after a long time away: "I was glad to be home. Free to do what I wanted." (Fiona). There was a sense of relief and of breaking free from the routine that was placed upon people at the unit. The transition to

home was a difficult one, but positive as the person was back in their own surroundings where they could regain a sense of control over their life.

## **HEALTHCARE IMPLICATIONS OF THE STUDY FINDINGS**

The aim of this chapter was to present a particular qualitative approach suited to understanding lived experience, meaning-making and the psychological responses of patients (and their significant others) within a certain healthcare setting. We chose to illustrate this via a study of a mechanical ventilation weaning unit, using the method of IPA. The aim of the study was to gain an understanding of the experiences of patients and family members who had spent time on a mechanical ventilation weaning unit, with a view to understanding psychological considerations. There are key implications for weaning units, such as that drawn on in this research.

‘Being different’ was an experience highlighting participants’ feelings of being special in some way. The unit actively selects people for admission. This led to a feeling amongst people admitted that they were special and had something different about them which meant they would be a good candidate. The feeling of being different and special by participants could be used to shape how conversations are had prior to people being admitted to the hospital. It was important for participants that they were offered a service over which they had a choice whether to attend or not. Therefore, conversations with patients and family about moving to the unit should revolve around what makes them a suitable candidate and how they might be different to other people who would not be admitted to the unit.

The ability to be together during this difficult period was vital for patients and their significant others, and the environment of the unit afforded both opportunities for community but also times of isolation and loneliness. Being visited helped to prevent patients from feeling low or depressed. When visitors left, people admitted to the unit relied on the sense

of community that the unit offered. The study also echoes previous research which has identified the importance patients place on being able to rely on family members for support (e.g., Arslanian-Engoren & Scott, 2003). The current study extends this work to show how, by taking the importance of support on board and being flexible with visiting hours, people are made to feel special and display resilience to low mood, anxiety and other psychological difficulties. Clearly, the features that supported community or added to feelings of isolation and loneliness should be maximised and minimised respectively as much as possible (e.g., flexible visiting, opportunities for patients to socialise, outpatient care that maintains the continuity of care).

Contrary to other research (e.g. Arslanian-Engoren & Scott, 2003; Cook, et al., 2001; Wunderlich, et al., 1999), no mention was made of psychological difficulties which impeded the weaning process. However, participants did indicate they experienced psychological difficulties at the time of transition from the unit to home. Both people who had been admitted to the unit and their family members felt this distress. The process of going home is a simple one but for most it is long and difficult with considerable psychological barriers. Therefore, the provision of psychological support would be of particular use here in supporting both patients and family members in continuing their recovery at home, as this transition period evokes particular and difficult emotions.

## **Conclusion**

Within this chapter we have presented the qualitative approach of Interpretative Phenomenological Analysis and applied it to the setting of a mechanical ventilation weaning unit. The study demonstrates how the application of qualitative research methods can be used to guide and develop practices and procedures in healthcare delivery settings. Although the present findings offer particular issues of consideration for specialist mechanical ventilation

weaning units and ICUs, our description and application of IPA here serves an illustrative purpose for others interested in applying qualitative methods for similar purposes to other healthcare settings.

## REFERENCES

Arslanian-Engoren, C. & Scott, L.D. (2003) The lived experience of survivors of prolonged mechanical ventilation: A phenomenological study. *Heart & Lung: The Journal of Acute and Critical Care*, 32: 328-334.

Ayalon, L. (2007) The potential role of dependency in the weaning process: The case of a 57-year-old woman connected to a mechanical ventilator. *Clinical Case Studies*, 6(6), 459-467.

Boles, J.M., Bion, J., Connors, A., Herridge, M., Marsh, B., Melot, C., Pearl, R., Silverman, H., Stanchina, M., Vieillard-Baron, A. & Welte, T. (2007) Weaning from mechanical ventilation. *European Respiratory Journal*, 29(5), 1033-1056.

Boserman, C. (2009) Diaries from cannabis users: an Interpretative Phenomenological Analysis. *Health*, 13(4), 429-448.

Cook, D. J., Meade, M. O. & Perry, A. G. (2001) Qualitative studies on the patient's experience of weaning from mechanical ventilation. *Chest*, 120(6 suppl), 469S-473S.

Dreyer, A., & Nortvedt, P. (2008). Sedation of ventilated patients in intensive care units: relatives' experiences. *Journal of Advanced Nursing*, 61(5), 549-556.

Happ, M. B., Swigart, V. A., Tate, J. A., Arnold, R. M., Sereika, S. M. & Hoffman, L. A. (2007). Family presence and surveillance during weaning from prolonged mechanical ventilation. *Heart & Lung: The Journal of Acute and Critical Care*, 36(1), 47-57.

- Henneman, E., Dracup, K., Ganz, T., Molayeme, O., Cooper, C.B. (2002) Using a collaborative weaning plan to decrease duration of mechanical ventilation and length of stay in the intensive care unit for patients receiving long-term ventilation. *American Journal of Critical Care*, 11(2), 132-40.
- Huang, T. T. & Peng, J. M. (2010). Role adaptation of family caregivers for ventilator-dependent patients: transition from respiratory care ward to home. *Journal of Clinical Nursing*, 19(11-12), 1686-1694.
- Jablonski, R.S. (1994) The experience of being mechanically ventilated. *Qualitative Health Research*, 4,186-207.
- Jenny, J. & Logan, J. (1996) Caring and comfort metaphors used by patients in critical care. *Journal of Nursing Scholarship*, 28(4), 349-352.
- Logan J, Jenny J. (1997) Qualitative analysis of patients' work during mechanical ventilation and weaning. *Heart & Lung: The Journal of Acute and Critical Care*, 26, 140-47.
- Mendel, J.G & Khan, F.A. (1980) Psychological aspects of weaning from mechanical ventilation. *Psychosomatics*, 21, 465-471.
- Mulveen, R. & Hepworth, J. (2006) An interpretative phenomenological analysis of participation in a pro-anorexia internet site and its relationship with disordered eating. *Journal of Health Psychology*, 11(2), 283-296.
- Murray, C. & Rhodes, K. (2005) The experience and meaning of adult acne. *British Journal of Health Psychology*, 10(2), 183-202.

Mustfa, N., Walsh, E., Bryant, V., Lyall, R.A., Addington-Hall, J., Goldstein, L.H., Donaldson, N., Polkey, M.I., Moxham, J. & Leigh, P.N. (2006) The effect of noninvasive ventilation on ALS patients and their caregivers. *Neurology*, 66(8), 1211-1217.

NHS Modernisation Agency. (2001) Critical care programme: Weaning and long term ventilation. Leicester, England: NHS Modernisation Agency. Retrieved from [http://www.ics.ac.uk/intensive\\_care\\_professional/critical\\_care\\_programme\\_-\\_weaning\\_and\\_long\\_term\\_ventilation\\_](http://www.ics.ac.uk/intensive_care_professional/critical_care_programme_-_weaning_and_long_term_ventilation_).

Palmer, M., Larkin, M., de Visser, R. & Fadden, G. (2010) Developing an interpretative phenomenological approach to focus group data. *Qualitative Research in Psychology*, 7(2), 99-121.

Seneff, M.G., Wagner, D., Thompson, D., Honeycutt, C. & Silver, M.R. (2000) The impact of long-term acute-care facilities on the outcome and cost of care for patients undergoing prolonged mechanical ventilation. *Critical Care Medicine*, 28(2), 342-350.

Smith, J. A. (2004) Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1(1), 39-54.

Smith, J. A. (2011) Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review*, 5(1), 9-27.

Smith, J. A., & Osborne, M (2008) Interpretative Phenomenological Analysis in Smith, J.A. (ed.) *Qualitative psychology: A practical guide to research methods*. (2nd Edition) London, Sage, pp. 53-79.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London, Sage.

Smith, J. A., Jarman, M. & Osborn, M. (1999) Doing interpretative phenomenological analysis. In Murray, M. & Chamberlain, K. (eds.), *Qualitative health psychology: Theories and methods*. London, Sage, pp. 218-240.

Wise, M.P., Hart, N., Davidson, C., Fox, R., Allen, M., Elliott, M., Winter, B., Morgan, M., Shovelton, H., Meadowcroft, R. & Campbell, J. (2011) Home mechanical ventilation. *British Medical Journal*, 342, p.d1687.

Wunderlich, R.J., Perry, A., Lavin, M.A. & Katz, B. (1999) Patients' perceptions of uncertainty and stress during weaning from mechanical ventilation/Educational STATPack. *Dimensions of Critical Care Nursing*, 18(1), 2.

<b>Participant pseudonym</b>	<b>Status</b>	<b>Relationship to another participant</b>
<b>Alan</b>	Former inpatient on weaning unit	Partner of Bernice
<b>Bernice</b>	Significant other (spouse)	Partner of Alan
<b>Carol</b>	Significant other (mother of Ian, former patient, who was not interviewed)	N/A
<b>Dan</b>	Former inpatient on weaning unit	Partner of Helen
<b>Eddie</b>	Significant other (spouse)	Partner of Fiona
<b>Fiona</b>	Former inpatient on weaning unit	Partner of Eddie
<b>Helen</b>	Significant other (spouse)	Partner of Dan

*Table 1: Participant pseudonyms and relationship to other participants*



<b>Example topics for person who had been weaned</b>	<b>Example topics for significant other</b>
<p>Expectations of the unit (what did you expect from staff?)</p> <p>Psychological impact of being on the unit (how did you feel when you moved there?)</p> <p>Emotional support (did you get any? Where did this come from?)</p>	<p>Experience of visiting the unit</p> <p>Experience of the weaning process (were you there for any this process?)</p> <p>Psychological impact of having a loved one on the unit (did this change at all?)</p>

*Table 2: Example topics and prompt questions from interview schedules*