

Section 3: Critical Appraisal

Laurence Regan

Trainee Clinical Psychologist

Doctorate in Clinical Psychology

Faculty of Health and Medicine

Division of Health research

Lancaster University

Word count: 3311 (Excluding References and Appendices)

Corresponding author address:
Laurence Regan
Doctorate in Clinical Psychology
C14 Furness College
Lancaster University
Lancaster, UK
LA1 4YG
Email: l.regan@lancaster.ac.uk

Prepared for submission to Mortality

Critical Appraisal

This essay aims to provide reflections on different research paradigms in clinical psychology and how this influenced my choice of research methodology. Further, I reflect on the research process including data collection and analysis. I aim to increase the integrity of my study by demonstrating reflexivity through critical consideration of my positions.

Historically, the pervasive idea that quantitative research is superior and the only way of yielding valid, useful data has led to quantitative methods dominating research. This led to the rise of behaviourism (Watson, 1913), which heralded the rejection of introspection and the rise of interest in observable (and therefore measurable) phenomena. The dominance of quantification is evidenced in the distinction between ‘hard’ and ‘soft’ sciences and the arts, and the resulting hierarchy seen in national curriculum (Taylor & Andrews, 2012). Similarly, this view is enshrined in the National Institute for Health and Clinical Excellence (NICE) hierarchy of research for evidence-based medicine (Kelly et al., 2010). The hierarchy of evidence is ranked largely based on the likelihood of bias (Burns, Rohrich, & Chung, 2011). Consequently, randomised-controlled trials (RCTs) are the gold standard for evidence because bias is reduced through a range of methodological constraints, including tight control of confounding variables and random allocation to conditions, whereas case studies or expert opinions may be ‘biased’ by the investigator’s beliefs or experience.

This is particularly relevant for clinical psychology as a profession, which, certainly in the UK, sits in a healthcare system dominated by the medical model. Moreover, there is increasing scrutiny in mental health provision, not only to demonstrate the effectiveness of treatments but also their cost-effectiveness.

Psychotherapy, a large part of the work of clinical psychologists (Division of Clinical

Psychology, 2010b), does not easily lend itself to randomised, double blind, placebo-controlled trials, as does pharmacotherapy. However, clinical psychologists and other psychotherapy researchers have responded to the demand for scientific validity by producing high quality research publications demonstrating the efficacy of therapy, for example, cognitive behavioural therapy (CBT) for anxiety (Hofmann & Smits, 2008) and depression (van Straten, Geraedts, Verdonck-de Leeuw, Andersson, & Cuijpers, 2010). This has resulted in the ascendancy of evidence-based practice in therapy analogous to evidence-based medicine (Kazdin, 2008). Accordingly, clinical psychology appears to have cemented its status as an evidence-based profession yet in doing so has whole-heartedly but perhaps unwittingly subscribed to the superiority of quantitative research.

Guba and Lincoln (Guba & Lincoln, 1994) offer some arguments to the “received view” of science. One of their main criticisms is that quantitative approaches are so exclusionary and stripped of context that they detract from the study’s relevance and real-world applicability. They also contend that quantification excludes meaning and purpose and consequently it is impossible to understand human behaviour in this way. In a similar vein, Patel (2003) argues that historically clinical psychologists have neglected the social, historical and political contexts that determine distress in favour of individualised understandings that reinforce inequality and oppression.

Reflecting on this issue at the stage of generating a research question and methodology, I was compelled to ask – what counts as evidence? A commitment to the pursuit of truth is a worthy endeavour. Yet there are serious difficulties in understanding what truth is (Lynch, 2001). Furthermore, if the sole focus of research is quantifiable data, alternative ways of understanding and explaining phenomenon are going to be overlooked. One of my primary concerns from the inception of this study was

researching illness without perpetuating the medical model of ‘mental illness’. In the UK, the Division of Clinical Psychology’s (DCP) Good Practice Guidelines on the Use of Psychological Formulation (2010a) and the British Psychological Society’s (BPS) Guidelines on Language in Relation to Functional Psychiatric Diagnoses (The British Psychological Society, 2015) both suggest that clinical psychologists should take a psychological perspective rather than relying on diagnosis. I resolved not to contribute to the ubiquitous medicalisation of distress (Mulder, 2008) that is particularly relevant in health settings, in my own research.

My first encounter with this systemic bias towards quantitative methodologies was during the ethics application stage, which was a lengthy and arduous procedure. One of the reasons my ethics application was not initially considered for review was that I submitted an example topic guide, which I stated would be subject to change based on service user involvement and subsequent interviews. I was informed that my ethics application would not be accepted unless the finalised interview schedule was specified.

I experienced this as restrictive and inhibiting and felt compelled to negotiate conditions that do not readily transfer to qualitative research. Ritchie, Lewis, Nicholls and Ormston (2014) suggest that a topic guide is a tool for guiding the discussion rather than an exact prescription of the questions to be asked. They contend that use of topic guides in a rigid way will inhibit the development of potentially interesting but unexpected themes as well as the reflection of the researcher and participant. More widely, Sim and Wright (2000) argue that the subject of exploratory research by definition is one that is not fully understood. The authors further suggest that this ambiguity makes it impossible to detail prospectively the means by which data are to be collected. Compiling a coherent topic guide was a challenge – in practice it was a living document that changed with each interview I completed. Questions were added,

removed, phrased in different ways or asked in a different order as a result of information gathered from previous interviews.

It is of course imperative to conduct research ethically. Anfara, Brown and Magione (2002) argue that public disclosure of methods of data collection and analysis in qualitative research are often absent. Furthermore, the authors suggest that the “qualitative ethic” (p.21) necessitates that researchers corroborate their interpretations and results by publicising the processes of their research. Similarly, Yardley (2000) proposes transparency as a key criterion for rigour and quality in qualitative research. Accordingly, in an effort to act ethically and transparently, the final interview schedule is appended (see Appendix 1), as well as the initial approved version which forms part of the appendix in the empirical paper.

Through clinical training, I have been introduced to alternatives to the positivist approach to knowledge construction. The basic principle of qualitative research is to obtain rich, contextual understandings of people’s experiences, perspectives and histories. More specifically, phenomenology is concerned with studying experience and describing it from the perspective of the individuals concerned. Dougherty (2002) suggests that our social world is complex and inherently bound by relational interactions. A phenomenological exploratory qualitative research interests me for this reason. I enjoy the challenge of trying to understand and interpret human motivations and behaviour from the perspective of the individuals concerned. I believe that research is an interpersonal process and that knowledge cannot be regarded as universal; rather it is local, temporary, and context-dependent. Epistemologically, phenomenological approaches are rooted in subjectivity and personal knowledge (Lester, 1999).

Although exploratory research differs from experimental design, the legitimate problem of ‘bias’ with qualitative research remains. Are my findings valid? Who do

they represent – me or the participants or both? Who do they benefit? While I feel comfortable in rejecting the notion of objectivity, there is still a need to gauge knowledge.

One method of ensuring quality in quantitative research is reflexivity. Pillow (2003, p.178) suggests that reflexivity involves the researcher taking a “critically conscious” stance, identifying his/her own positions in relation to the research (this may be, for example, gender, race, class, sexuality or ethnicity) and exploring how they influence the research process. Rather than seeing researcher ‘bias’ as threatening to the validity and reliability of data, a reflexive approach offers the view that involvement of the researcher can be a resource to the research process (Anderson, 1991). This reflexive approach to research accords with the DCP’s recent adoption of a reflective scientist-practitioner perspective (DCP, 2010a).

Furthermore, crucial to a phenomenological approach is “bracketing” the researcher’s own assumptions and perceptions (Lester, 1999, p.1). I acknowledge that I hold a privileged position, because I am young, male, able-bodied and well educated. I am an atheist, with a lack of belief in gods. Further to this, I believe that in the UK there is a historic privileging of Christian values that endures today, exemplified by the laws on assisted dying. Moreover, despite the impressive work of palliative care professionals, I believe that not every death can be ‘good’ and that, as a civilised society, we should legalise assisted dying. I passionately believe in the right to autonomy and believe that our lives and bodies are our own and the limits to autonomy and freedom should be drawn as narrowly as possible.

Prior to data collection, I recognised that these views might be very different from those held by the people I would interview. For example, older people may be more inclined to be unquestioning and accepting of paternalistic medicine or religious

people may believe in the sanctity of life under all circumstances. In response to this I tried to set these assumptions aside during data collection and be open to alternative viewpoints (Smith, 2007) to be able to enter the subjective worlds of the participants

Additionally, I tried to assume a stance of neutrality but also genuineness. The tension in trying to occupy both positions resulted in some missed opportunities. A number of times in early interviews after switching off the Dictaphone participants continued conversation with me and asked my views on assisted dying. I cautiously volunteered my opinions on the issue and occasionally participants would expand on their points or volunteer new information. In hindsight, this was rich, co-constructed data that was lost to the study because I was in thrall to positivist ideas and fearful of biasing the data. It was only subsequently during later interviews that I considered myself to be a co-constructor of the research while being mindful of leading participants to say what I want to hear. In future studies, I will endeavour to be reflexive at every stage of the research process by taking ownership of my views while being considerate of how I might influence participants' accounts.

I offered participants the choice of being interviewed face-to-face or by phone. Initially I felt relieved when more people opted for phone interviews because face-to-face interviews take up more time, which I could scarcely afford as a result of the time limits on my study. However, I also felt uneasy because I thought that interviews might be less rich or meaningful as a result of the reduced information that non-verbal cues might elicit. A study by Sturges and Hanrahan (2004) compared the two modes and found no significant differences in results, concluding that telephone interviews can be used productively in qualitative research. Additionally, sensitive topics may be more easily broached with the comparative anonymity provided by telephone interviews (Fenig, Levav, Kohn, & Yelin, 1993). Consistent with this research, I was relieved to

perceive no difference in quality between telephone and face-to-face interviews and was reassured in my decision to honour the preferences of individuals and offer a variety of inclusive ways to participate in my study.

Reflexivity was particularly relevant in a telephone interview situation with one participant who talked at length about topics that were irrelevant to the research question. I felt anxious about these detours and wanted to bring him back to the purpose of the interview. However, I felt unable to raise this explicitly and there was no possibility of doing this nonverbally. I was conscious of our fragile and temporary bond and did not want my actions to be interpreted as rude and risk the participant feeling silences and unwilling to speak further. On reflection, I feel that I was acutely aware of my status as a trainee and influenced by a desire to appear competent and manage the interview well. Following this incident, I considered ways to manage my anxiety and bring someone respectfully back to the point of our conversation but also how to manage my expectations. Although many of the anecdotes and supplementary detail provided by participants were not within the scope of this study and did not form part of the findings – clearly they were important for the individual and added further contextual information and so should be respected. By the end of the data collection phase, I was able to be mindful of my anxieties as a trainee and bracket them. Consequently, interviews became more fluid conversations and I became aware that I was co-creating the data, not gathering it through a list of pre-determined questions.

Moreover, during the data collection stage, I was aware of sameness and difference between participants and me. I heard poignant stories of families struggling with the protracted suffering and death of a loved one, which resonated with me. There is a history of Alzheimer's in my family and consequently I have witnessed the impact of loss as a result of neurodegenerative disease on loved ones, particularly my

grandfather whose mother and brother died in care homes. I also felt drawn into engaging in more therapeutic dialogues with participants, particularly at times when they became tearful during interview. I felt disappointed and frustrated that the needs of people with HD are routinely not being met. I attended to these impulses and feelings and drew on transferable therapist skills to contain and manage them.

Apart from experiencing strong emotions from empathising with participants, often the processes of research felt mysterious and therefore threatening and anxiety provoking. Research supervision was helpful in providing a containing space for emotions. Another important function of supervision was offering a level of scepticism and detachment, which I lacked due to my close proximity to the data.

Feedback from supervisors offered new perspectives and developed my understanding of qualitative research. In particular, during the analysis stage of research, supervision was useful for discussing emerging themes and developing my interpretations. For example, the prodromal theme: 'HD threatens identity' was discussed in supervision in relation to novelty and theoretical value. My supervisor probed me to revisit the data and directed me to relevant clinical health psychology literature. I re-immersed myself in the data and returned to an unused but salient theme: 'Life-affirming aspects of HD'. These two themes and another initial theme: 'Family experiences shape views on assisted dying' were re-examined and integrated to comprise the finalised theme: 'HD threatens identity but is part of life'.

There is no single correct way to analyse qualitative data and it is difficult to demonstrate that the findings constructed by the researcher accord with the reality of the phenomenon studied (Anfara et al., 2002). However, the purpose of highlighting this process is to allow further scrutiny of my work to enhance its quality and defensibility.

To return to my earlier questions, I believe my findings are valid and representative of both the participants and me, as co-constructors of meaning. Patai (1994, p.70) asserts: “we do not escape from the consequences of our positions by talking about them endlessly”. I agree with this argument but believe that by making my views and actions available as much as possible I have worked to deconstruct my values as well as take accountability for the implications of my research.

Participant recruitment was a major challenge

I wanted to create a space to reflect on the challenges of researching a controversial subject within a small, hard to reach population. Participant recruitment comprised an array of activities including attracting potential participants, identifying eligible participants, adequately explaining the study to them, allowing them time to consider information, recruiting an adequate sample, gaining informed consent and organising interviews.

At each step of this journey there are potential pitfalls. Eighteen potential participants expressed interest in the study, yet only seven completed interviews. It is difficult to speculate on reasons why 11 participants ultimately did not take part. One person did not meet inclusion criteria due to being a family member of affected individuals but not having the gene himself. One person agreed to take part but withdrew on the day of interview citing mental health reasons. Three more people withdrew without specifying reasons and seven did not make further contact after opt-in.

Although more participants would have been desirable for diversity of opinion, I believe that refusing to consider alternative methods of attracting participants such as incentives ultimately contributed to gaining authentic, valid data. All participants demonstrated a willingness to take part, gave their time freely and had ample opportunity to withdraw.

The one participant who did not envisage a situation where he would choose assisted dying was a man. He eloquently put forward the case for the legalisation for assisted dying, yet thought it would be “cowardly” to elect personally to do this. This fits into the battle narrative described in *Dilemmas in decision-making on assisted dying*: “*There are no winners*”. It is suggestive of discourses around masculine identity, with the virtues of bravery and endurance favoured. This offers a potential explanation as to why women were over-represented in the sample.

Moreover, with a self-selected sample, it may be that those who participated in the study were more willing to discuss the topic due to being more open to assisted dying themselves. It is also possible that people with equally strong views who do not support the legalisation of assisted dying did not take part in research based on assumptions about my position on the issue.

Early on in the recruitment phase, I received a complaint about my study via the faculty ethics committee. I was notified by urgent email not to respond to any potential participants who might have made the complaint. I felt anxious and out-of-control, which was tempered somewhat by the knowledge that my study had received ethical approval. Although there were no repercussions resulting from the complaint, this incident encouraged me to reflect on the study of controversial issues. Lee and Renzetti (1990) define socially sensitive research as that which potentially has threatening implications or consequences for those involved. My research topic obviously has deep personal meaning for the people being researched, but is also concerned with the law around life and death and therefore inherently sensitive and threatening. Many disability rights groups oppose the legalisation of assisted dying based on the assumption that it might exert pressure on vulnerable people to choose this option to avoid being a burden on others. I believe that this is a strong argument against assisted dying, particularly in

the context of austerity in the UK and the narrative of disabled people as ‘scroungers’ or a burden on the state. However, I also believe that all new laws are a potential “slippery slope” to somewhere unintended and potentially dangerous. The purpose of the law is to define precisely the limits of behaviour. Moreover, protecting and improving the quality of life of people with life-limiting illnesses is not mutually exclusive from legalising assisted dying.

Research with the potential to produce controversial findings is often met with resistance, not least within the scientific community (Armstrong, 1995). I believe it is of the utmost importance to research these areas. The BPS Code of Human Research Ethics (BPS, 2014) discusses respect, competence, responsibility and integrity but it does not address the core purposes of research – to explore, describe and explain phenomena. Tautological inquiries will not provide useful information and so it is important not to circumvent genuine discovery and progress in the pursuit of ethical research.

Conclusion

My empirical paper explored the views and beliefs of people with HD about the concept of assisted dying in a country where this option is unavailable. It revealed that people with HD consider historical family experiences and hypothetical futures in constructing their views on assisted dying. They place importance on autonomy and control. Furthermore, they identified numerous dilemmas in decision making exist and limited discussion about HD and end-of-life care. This critical appraisal has further illuminated my research process and offered some personal reflections that influenced it.

References

- Anderson, J. M. (1991). Reflexivity in Fieldwork: Toward a Feminist Epistemology. *Image: The Journal of Nursing Scholarship*, 23(2), 115–118. doi:10.1111/j.1547-5069.1991.tb00654.x
- Anfara, V. A., Brown, K. M., & Mangione, T. L. (2002). Qualitative Analysis on Stage: Making the Research Process More Public. *Educational Researcher*, 31(7), 28–38. doi:10.3102/0013189X031007028
- Armstrong, J. S. (1995). Publication of Research on Controversial Topics: The Early Acceptance Procedure. *International Journal of Forecasting*, 11. Retrieved from <http://papers.ssrn.com/abstract=668139>
- British Psychological Society. (2014). Code of Human Research Ethics. *British Psychological Society*, 1(1), 1–44. doi:180/12.2014
- Burns, P. B., Rohrich, R. J., & Chung, K. C. (2011). The Levels of Evidence and Their Role in Evidence-Based Medicine. *Plastic and Reconstructive Surgery*, 128(1), 305–310. doi:10.1097/PRS.0b013e318219c171
- Division of Clinical Psychology. (2010a). Good practice guidelines on the use of. doi:10.3265/Nefrologia.pre2011.Apr.10797
- Division of Clinical Psychology. (2010b). The core purpose and philosophy, 1–16. Retrieved from [www.bps.org.uk/system/files/Public files/DCP/cat-713.pdf](http://www.bps.org.uk/system/files/Public%20files/DCP/cat-713.pdf)
- Dougherty, D. (2002). Grounded Theory Research Methods. In L. McCann & J. A. Baum (Eds.), *The Blackwell Companion to Organizations* (Wiley-Blac., pp. 849–867).
- Fenig, S., Levav, I., Kohn, R., & Yelin, N. (1993). Telephone vs face-to-face interviewing in a community psychiatric survey. *American Journal of Public Health*, 83(6), 896–8. Retrieved from

<http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1694719&tool=pmcentrez&rendertype=abstract>

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. . Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105–117). SAGE Publications.

Hofmann, S. G., & Smits, J. A. J. (2008). Cognitive-behavioral therapy for adult anxiety disorders: a meta-analysis of randomized placebo-controlled trials. *The Journal of Clinical Psychiatry*, *69*(4), 621–32. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/18363421>

Kazdin, A. E. (2008). Evidence-based treatment and practice: New opportunities to bridge clinical research and practice, enhance the knowledge base, and improve patient care. *American Psychologist*, *63*(3), 146–159. doi:10.1037/0003-066X.63.3.146

Kelly, M., Morgan, A., Ellis, S., Younger, T., Huntley, J., & Swann, C. (2010). Evidence based public health: A review of the experience of the National Institute of Health and Clinical Excellence (NICE) of developing public health guidance in England. *Social Science & Medicine* (1982), *71*(6), 1056–62. doi:10.1016/j.socscimed.2010.06.032

Lee, R. M., & Renzetti, C. M. (1990). The Problems of Researching Sensitive Topics: An Overview and Introduction. *American Behavioral Scientist*, *33*(5), 510–528. doi:10.1177/0002764290033005002

Lester, S. (1999). An introduction to phenomenological research. Retrieved February, *18*(2), 1–4. doi:10.1111/j.1467-9450.1984.tb01000.x

Lynch, M. P. (2001). *The Nature of Truth: Classic and Contemporary Perspectives*. MIT Press. Retrieved from

<https://books.google.com/books?hl=en&lr=&id=zXzEP1SgMz8C&pgis=1>

Mulder, R. T. (2008). An epidemic of depression or the medicalization of distress?

Perspectives in Biology and Medicine, 51(2), 238–50. doi:10.1353/pbm.0.0009

Patai, D. (1994). When Method Becomes Power. In A. D. Gitlin (Ed.), *Power and Method: Political Activism and Educational Research* (p. 248). Psychology Press.

Retrieved from

<https://books.google.com/books?hl=en&lr=&id=DamX6kuQqYQC&pgis=1>

Patel, N. (2003). Clinical Psychology: Reinforcing Inequalities or Facilitating

Empowerment? *The International Journal of Human Rights*, 7(1), 16–39.

doi:10.1080/714003792

Pillow, W. (2003). Confession, catharsis, or cure? Rethinking the uses of reflexivity as methodological power in qualitative research. *International Journal of Qualitative*

Studies in Education, 16(2), 175–196. doi:10.1080/0951839032000060635

Ritchie, J., Lewis, J., Nicholls, C., & Ormston, R. (2014). Qualitative Research Practice:

A Guide for Social Science Students and Researchers. *Qualitative Research*, 356.

doi:10.4135/9781452230108

Sim, J., & Wright, C. (2000). *Research in Health Care: Concepts, Designs and*

Methods. Nelson Thornes. Retrieved from

<https://books.google.com/books?hl=en&lr=&id=vwjhgtUoNZIC&pgis=1>

Smith, J. A. (2007). *Qualitative Psychology: A Practical Guide to Research Methods*.

SAGE Publications. Retrieved from

<https://books.google.com/books?hl=en&lr=&id=D5xHYpXVDaAC&pgis=1>

Sturges, J. E., & Hanrahan, K. J. (2004). Comparing Telephone and Face-to-Face

Qualitative Interviewing: a Research Note. *Qualitative Research*, 4(1), 107–118.

doi:10.1177/1468794104041110

Taylor, R., & Andrews, G. (2012). *The Arts in the Primary School*. Routledge. Retrieved from https://books.google.com/books?id=Tv2o5Gr_ULUC&pgis=1

The British Psychological Society. (2015). Guidelines on Language in Relation to Functional Psychiatric Diagnosis, (March), 1–8. Retrieved from [http://www.bps.org.uk/system/files/Public files/guidelines_on_language_web.pdf](http://www.bps.org.uk/system/files/Public%20files/guidelines_on_language_web.pdf)

van Straten, A., Geraedts, A., Verdonck-de Leeuw, I., Andersson, G., & Cuijpers, P. (2010). Psychological treatment of depressive symptoms in patients with medical disorders: A meta-analysis. *Journal of Psychosomatic Research*, *69*(1), 23–32. doi:10.1016/j.jpsychores.2010.01.019

Watson, J. B. (1913). Psychology as the behaviorist views it. *Psychological Review*, *20*(2), 158–177. doi:10.1037/h0074428

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, *15*(2), 215–228. doi:10.1080/08870440008400302