

POGP CONFERENCE 2017

Finding your inspiration in the clinic: my experience of research

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Abstract

Conducting research need not be an intimidating prospect. It starts with a desire to understand something in more detail. We all experience moments when we question what is happening to a patient, and the best studies stem from attempts to get to the bottom of something that you have encountered. Knowing why you are interested in an area is initially more important than thinking that you understand exactly what you want to find out; this is because you will inevitably end up with more questions than answers. Keeping sight of the greater motivation for your research will carry you through the tougher parts of the work. The author discusses her own experience of carrying out a study: the highs, lows and challenges of the process, and the surprising benefits, which range from developing a supportive professional mentoring network to testing her own critical thinking and writing ability. Clinical research is the backbone of best practice. It is achievable within your own clinic, and offers you an opportunity to be an agent of change for both your patients and the profession.

Keywords: best practice, bladder pain syndrome, clinical research, inspiration, professional mentoring.

Introduction

I would like you to take a moment to think about the last patient whom you feel you treated well, the one who walked out of your clinic with a smile and a better quality of life because of what you did. Now think about the patient who got away, the one who sticks out in your mind as an unresolved challenge. You may have seen her for months or just moments, but she stays with you. I will call mine “Hannah”: she came into the room bent over, making small, shuffling, painful steps, as if the sheer act of walking would break her. She sat down awkwardly, with her hands clutching her lower abdomen, and told me her story:

“It’s this pain, it’s just taken over everything.... It burns inside.... I can’t do anything with the kids, I can’t go anywhere because I don’t know if there’ll be a toilet.... I have to go all the time, or it’ll get even worse.... It’s like I’m being stabbed up

inside.... It’s getting worse.... I don’t understand because they did all the tests then told me nothing’s wrong, but it all feels wrong.... He thinks I don’t love him because, you know, we can’t do the things that couples should.... It’s like razorblades....”

It may be that Hannah caught me in a particularly empathetic mood, or that her search for answers and, more importantly, help reminded of my own experiences within the healthcare system. Whatever was the case, her story and her pain remained with me for a long time. As I tried my hardest to understand Hannah’s symptoms and find ways to address her treatment, I was aware that I genuinely could not grasp her condition. Therefore, I began to read everything I could access online about bladder pain syndrome (BPS), or “interstitial cystitis”, as the condition is also known. The literature led me to places that I had not considered before, and gave me new perspectives on the problem. However, I did not have the skills to decide what was or was not useful, and I found no answers to provide me with

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practical steps that I could take to ease Hannah's suffering.

The more that I read, the more that pieces of the jigsaw fell into place, but it seemed like the puzzle was also expanding! I became obsessed with trying to understand how underlying autonomic changes could create symptoms, and how adaptations of the microbiome could increase those indications. However, I was still a long way from offering Hannah any practical help. Therefore, I completed every pelvic pain course I could find over the next few years, but although my skills improved, I still had questions.

I began my Master's degree at the University of Bradford, Bradford, UK, out of pure curiosity and a strong desire to better understand pelvic pain. I learned many things over the following 3 years, and I am now going to share my research journey with you.

Finding inspiration: your "why" is more important than "what"

My research journey started and ended with Hannah. Most of us will have experienced a time in our lives that we can pinpoint as the moment when something happened, or something changed; for example, when you met your life partner, or when you took your first uncertain steps into the dark arts of pelvic health. Although I did not know it at the time, my first encounter with Hannah was a pivotal moment in my professional life. She started me on my current career path – to explore, understand and explain pelvic pain – and for now, pain related to the bladder.

I am very interested in why the bladder might be painful, or why the brain may consider it under threat and, therefore, decide that it hurts. I am fascinated by the reason why the pelvic floor goes into spasm – why does any muscle go into spasm? Take a step back and really ask yourself, "Why?" If we knew the reasons for BPS or the processes underlying it, we might be able to prevent the cascade of steps that leads to pelvic floor muscle tension driving urgency, or vulvodynia, and most importantly, understand how we – the therapist and the patient – can deal with it.

That was the first thing that I want to share with you: realizing why you want to explore something is much more important than knowing what you want to explore. My "why" was that I wanted to gain the knowledge and skills that I needed to improve not just Hannah's quality of life, but that of every patient with pelvic pain.

Furthermore, as my analytical mind developed over the course of my Master's degree studies, I wanted to know more specifically if there was a way that Hannah could treat or manage herself more effectively, which was a more realistic goal within my stretched National Health Service (NHS) caseload. If you lack the inspiration to look at an area in detail, you will struggle with all the tiny, frustrating elements that make up good research practice. However, if you keep sight of the bigger picture – your "why", your overarching reason for doing something – then you will find things much easier.

Doing the process

The point of doing a Master's degree is to go through the process; it is not necessarily about the outcome at all.

I investigated therapeutic wand use in a small group of women with BPS. Half the participants used the wand and half did not. Everyone involved received six, weekly sessions of physiotherapy that also included dietary advice and pelvic floor release work. The results were published in this journal (Bond *et al.* 2017).

All the participants showed signs of improvement after 6 weeks of pelvic floor treatment, but the group using the wand had got better faster. After another 6 weeks without treatment, the control group had maintained their benefits. Therefore, physiotherapy treatment had worked: the symptoms of BPS had improved, and this progress had been maintained. However, more importantly, the group using the wand appeared to have continued to improve.

It took approximately 4 months to conduct the actual tests, but 10 months and over 40 000 words of ethics paperwork were involved in getting to that point. This preparation included getting a non-medical friend to translate my whole patient information booklet into Welsh – he told me that he had had to find new words that he had never used before! There was also a great deal of administration involved in the testing process: calling consultant's secretaries to check on potential candidates for the trial; organizing participants; and working around the department's needs to make sure that I had a suitable venue for my research. I had not expected any of this!

The sheer volume of preparatory paperwork that you must do can feel overwhelming, but the further along I got with it, the more I felt that I truly understood my project. Furthermore, it simplified the research question, which became:

“Does using a wand enhance physiotherapy treatment in women with BPS?”

The process of repeating, refining and re-submitting my work forced me to improve the clarity of my writing, which vastly improved its quality in turn. In this sense, and for the right people, the MSc process does work. It produces better clinicians and better researchers by making them think deeply about why they are doing something, and what it is that they are doing.

Find your village

Something else that I learned was that it takes a village to complete research. The university is only there for general guidance, especially if, like me, you are undertaking distance learning. The detailed and practical side of doing actual research is up to you. One of the most valuable things that I did was to develop my own network of local and international clinicians, researchers and editors. I got better and better at asking for help, and the people I got in touch with knew people who also helped. This was how my village grew.

People were vastly more generous with their time and their knowledge than I ever thought possible. I was given help with: statistics when my trial did not conform to the textbooks; the convoluted 8-month ethics process that turned “IRAS” (Integrated Research Application System) into a swear word in my house; understanding overarching research theory; and developing a sustained and strongly evidence-based argument. Each person who challenged my reasoning and helped me to develop a more critical approach to the literature, the methodology, the trial or the analysis of the results allowed me to become a more-discerning and better-informed physiotherapist. The most grounding influence of all was that of my two fellow MSc students, and the best and most accurate information that I got was from them. We were all deeply involved with research theory, but each of us was investigating a different area. This made for very fertile ground for learning and sharing. They were a huge support: text messages late on a Sunday night showed that they too were also sitting in front of their laptops, not in bed before another busy week in the clinic. I shared their highs and lows, and I am hugely proud of what they achieved.

When I began the Master’s degree, some colleagues were negative about my decision to do it, and these opinions dented my confidence and

easily disrupted the momentum that I needed to maintain throughout a long period of work. However, the converse was also true: I never expected that the MSc would provide me with a group of professional mentors and friends whom I am likely to have for the rest of my life. Over the first 2 years of the course, around 20 physiotherapists from all over the UK and Ireland studied alongside me at Bradford. I keep in regular contact with all of them, and a similar number of people whom I met during my research year have also become my friends. My clinical practice now benefits from a wide array of international mentors, and I find myself taking part in more-informed debate online, and listening critically to different views about research and clinical experience.

Having more-informed clinicians engaging critically with each other, and with the national and international literature, can only enhance the profession. Finding your village need not be daunting: you can start by contacting your local hospital’s ethics team; the library; or even, like me, posting on the Facebook groups for POGP (www.facebook.com/groups/1652693234997631/) and Global Pelvic Physio (www.facebook.com/groups/1167050906649066/).

Learning to manage

Research requires commitment, of course. I have already talked about the importance of knowing why you are doing it, but without my interest in exploring pelvic pain providing my inspiration, I cannot imagine that I would have managed to make the sacrifices that the work demanded. I thought that I was prepared for it, but I really struggled to cope. I worked full-time and privately in my evenings during the first 2 years. This meant that I spent all my weekends and evenings at my desk with the curtains drawn, and lost a great deal of sleep. At the end of my second year, I burned out, left the NHS and went part-time in order to be able to complete the research. The cost of the degree then escalated: I lost one-third of my salary to regain my sanity.

The reality was that my time management and focus had initially been poor. I could sit at the laptop and procrastinate for an hour or more before beginning, but once again, the process won in the end. The requirement to sit down and get the job done, sacrificing social and family time, has made me more structured and focused when I work. I am vastly more productive than I

used to be, which now allows me to balance my work, my private business and my teaching more equally with family time and relaxation. I needed to do it to learn it.

Finding more questions than answers

All along, I wanted to get hard answers to the research question that I could use in the clinic. I wanted to know what I could do to make people better, and I wanted to understand why what we do helps our patients: why does treating pelvic floor tension myalgia reduce the symptoms of urgency and frequency in BPS? However, the reality of the timescale, the dearth of previous work in the area and my lack of research experience meant that I had to pilot my study. You do not get hard answers from pilots, but you do find even more interesting questions. In fact, a sign of good research is that you should get more questions than answers, and this is a joy. Now I have so many more questions that I want to answer:

- To what degree is using the wand therapeutic?
- Wand use is not for everyone, so what is the lived experience of the people we are asking to try it?
- Why does the pelvic floor reduce length and motility in pain states?

The reality is that, if you really want to find answers, you will follow the research until you get there, which may take decades. However, this process begins with inspiration, and it can start in your clinic next week.

Research into practice

So how did the story end for Hannah? I managed to track her down after I had finished the study, and took her through a full 12-week course of treatment with a wand. I am happy to say that she is now managing her symptoms very well. She rarely has any flare-ups of pain, and normal bladder function has been restored. It took me 4 years to get to the point where I had the beginning of an idea of how to treat her, which is what this is – just a beginning!

Working in the field of bladder pain is a truly exciting experience. We are at the forefront of pain science, and this area is always evolving. I now hope to share my learning with as many physiotherapists as I can. I hope that this will mean that they do not have to spend 4 years learning how to treat one patient, but can use what I have learned as a springboard.

Research is not just for academics. The process is about asking and answering questions, and exploring our work in ever-wider contexts. Completing my research challenged me both professionally and personally. I had a huge sense of accomplishment when I finally came to print and then submit my dissertation, one that I did not experience when I received my undergraduate degree. I felt that I had, in a small way, added to the knowledge about, understanding of and treatment for a complex condition, and done so in a way that may practically help clinicians.

I also grew as a physiotherapist. I used to feel nervous about my level of knowledge and skills, but I am now much more confident. Having embedded myself in the literature over the past 4 years, and having conducted my own research, I can now say with integrity that I am providing the best care that I can for my patients with BPS. I have also challenged my own long-held perceptions and beliefs with surprising literature, and found a level of motivation and drive within me that I did not know I had. I have also developed resilience and perseverance. These are all skills that I can use normal life, but are especially relevant to the wonderful work that we do.

Think back to that patient I mentioned above, the one who got away. What single thing would you like to have known that might have changed the way you felt about that person, or how you might have treated them? Now imagine how you could answer that question.

The answer does not have to be a long one. Some of the best research begins on a small scale in a clinical setting. Yours could start on Monday morning. It just needs a question to answer, a pinch of inspiration and very, very sustained curiosity.

Reference

- Bond J., Pape H. & Ayre C. (2017) Efficacy of a therapeutic wand in addition to physiotherapy for treating bladder pain syndrome in women: a pilot randomized controlled trial. *Journal of Pelvic, Obstetric and Gynaecological Physiotherapy* **120** (Spring), 12–27.

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