Practice Based Evidence:

A Pathway for Person-Centred Support

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Introduction

In our work as practitioners, empirical research can help us to determine the efficacy of the approaches that we use. The impact of empirical research cannot be underestimated. Such research can help us to make sense of the world around us, as well as influence the products we buy, the medical treatment we receive, and even our social and political views. However, this is not always a unilateral relationship. The views, interests and attitudes of social groups and communities can also influence the research that is conducted. In the past, research in fields such as biology, anthropology, psychology and sociology often served the implicit, or sometimes explicit, biases of the time. Academic researchers have found evidence to show that these biases remain present in empirical research, and can be affected by skin colour, ethnicity, religion, gender identity, sexual orientation, weight, physical, or mental disability, among others (Greenwald and Krieger, 2006; Staats et al., 2014). Calaza and colleagues (2021) discuss how scientific evidence shows the presence of implicit bias in the academic community, which contributes to significantly damaging unconscious evaluations and judgments of individuals or groups, such as Black and Latina women. In recent years, there has been a move towards making research more representative of the diversity that we see around us. As a practitioner, I believe that practitioners can work in partnership with researchers to bring about this change. In this article, I will be discussing this in the context of neurodiversity.

Evidence-Based Practice

Scientific research guides practice in a number of fields, which is referred to as evidence-based practice. In psychology, evidence-based practice is defined as the

integration of the best available research with clinical expertise in the context of patient characteristics, culture and preferences (American Psychological Association, 2005). In this article, we are concerned with the context of a person, described above as a 'patient,' and their experiences. If their experiences are not represented in the 'best available research,' then we must reflect on the evidence-based practices that we as practitioners are applying, and question whether these clinical practices are meeting the needs of the people we are supporting.

In what ways can the complexities of a person's presentation and lived experience be overlooked? Some researchers posit that evidence-based practice proposes a particular, deterministic version of rationality (Webb, 2001). Scientific research is often focused on what is 'measurable,' for example, behaviour and measurable outcomes are often observed in a controlled environment in an attempt to isolate the findings. When we apply this approach to the field of psychology, the nuance can sometimes be overlooked. More and more we are seeing that it is difficult to isolate single, measurable, observable items.

In measuring these outcomes, research methods in empirical research are often concerned with group comparison. These methods seek homogeneity within these groups, and attempt to control for any variance within that. For example, Randomised Control Trials (RCTs) are considered the gold standard in empirical research methodology (Beail, 2010). In RCTs, subjects/patients are randomly assigned one of two groups, experimental or control: those in the experimental group will receive the intervention that is being tested, and those in the control group receive an alternative intervention, or no intervention. RCTs look for group effects to assess the efficacy of an intervention.

In recent years, there has been a move towards research that is more inclusive and representative of groups. In order to inform clinical practice, it is imperative that empirical research is representative of the experiences of individuals. When large-scale RCTs have been employed to measure outcomes in the area of psychology, they have been criticised as they tend to overlook nuance and diversity in favour of viewing populations as homogeneous groups. RCTs can therefore have poor success in predicting outcomes at the individual level from data gathered at the level of group means (Margison et al., 2000). The importance of representative sampling is beginning to be further explored in the research (Hussain-Gambles, Atkin, & Leese, 2004).

Practice-Based Evidence

On the other hand, practice-based evidence integrates individual clinical expertise and service-level parameters with the best available evidence on research topics. This 'bottom-up' approach to gathering evidence contrasts with the 'top-down' approach utilised by RCTs (Freeman & Power, 2007). Practice-based studies are beginning to look at measures and controls for heterogeneity of patients, treatments, and outcomes seen in real-world clinical settings (Horn & Gassaway, 2010). Methodologies such as Comparative Effectiveness Research (CER) are put forward as an alternative to RCTs and explore what works best for specific patient presentations, which will then inform treatment recommendations for individual patients.

The concept of practice-based evidence is also becoming more commonly used to reflect practices in local communities and minority groups. Researchers in Native Communities in the United States have begun to develop and research

evidence-based practices that have been adapted to meet the needs of Native Americans, who may not be represented in other empirical research (Bartgis & BigFoot, 2010).

Scientific experimentation is based on measurable outcomes. In order to produce empirical research, psychology can sometimes oversimplify complex concepts such as emotion, social impairments and therapeutic approaches. Furthermore, in our goal to make research generalisable, we may be overlooking cultural and social contexts that can have implications for an individual's subjective experiences. When we look at lived experience, we can gain a more subjective description of psychological and social constructs. Empirical research attempts to control for confounding variables, but we cannot control for confounding variables in our practice, or in day-to-day life. Practice-based evidence incorporates the complexities of the wider context surrounding an individual's presentation. In practice-based evidence, real world practice is documented and measured as it occurs (Swisher, 2010).

Autism: The Medical Model of Disability vs The Neurodiveristy Paradigm

In recent years, there has been a call for more representative and inclusive research by autistic people. Historically, the production of empirical research in the area of autism has largely excluded autistic voices. In this article, I pose the question, if evidence-based practice is centred around developing clinical expertise in the context of patient characteristics, culture and preferences, then why does empirical research often overlook the contexts and experiences of autistic people? As practitioners, we must be aware that research can be biased, and that this bias can influence the trends

of therapeutic approaches and what is deemed as best practice for people in need of therapeutic input. Looking to practice-based evidence approaches may enable us to be more inclusive of the subjective experiences of neurodivergent people.

In research, autism is often viewed within two distinct approaches; the medical model of disability and the neurodiversity paradigm (Baron-Cohen, 2017). The medical model originates from the assumption that there is a right way of developing neurologically, and positions autism and other conditions as being in need of treatment (Ferenc, Byrka & Król, 2021). Within the medical model, differences can sometimes be viewed as abnormalities. In a study completed in 2018 that explored screening approaches in the diagnosis of autism, the authors noted that the 'questionnaire was completed by parents of children with autism (85), parents of normal children (65) and parents of children with Down syndrome (20)' (Mahmoudi et al., 2018). The use of the word 'normal' indicates that children with a diagnosis of autism or Down Syndrome are comparatively 'abnormal.' On the other hand, the neurodiversity paradigm (Singer, 1999) describes autism as a neurodivergence, and poses that there is a natural diversity to neurological development. This paradigm has developed through listening to autistic people and their subjective experiences. This approach moves away from the view that neurodivergence is abnormal or 'other.' When we approach conditions from this perspective, we can be more empathic in our practice. This shift towards a positive psychological approach to conditions such as autism enables practitioners to focus on strengthening a person's ability to cope with the challenges that face them (Groden, Kantor, Woodard, & Lipsitt, 2011).

When we exclude the lived experience of autistic people, we run the risk of ignoring their natural diversity. This could, in turn, lead to their natural diversity

becoming viewed as 'other' in the research that is produced, which further contributes to a lack of understanding around autistic people and their needs. Ueda & Okawa (2003) discuss the importance of the subjective dimension of disability, also called 'the subjective experience,' for the psychological well-being of the disabled person. Ferenc, Byrka and Król (2021) found that autistic adolescents self-reported on their own mental health differently to their parents' perception of their mental health. This shows the importance of working directly with a client, where possible, to develop an appropriate and effective person-centred therapeutic approach.

Applied Behavioural Analysis as Evidence-based Practice

When we consider evidence-based practice for supporting autistic people, one of the most commonly researched approaches is Applied Behavioural Analysis (ABA). Inputting this approach into any search engine or journal will yield a vast number of evidence-based research studies that show the efficacy of this model (Grey & Hastings, 2005). In 2019, it was estimated that the market value of this approach could be as large as $17 billion annually (Sandoval-Norton & Shkedy, 2019). From this basis, when we consider 'best available research' as a tenet of evidence-based practice, we can see how ABA became a commonly used practice in clinical settings. It is described as a 'precise, measurable and scientific method of changing behaviour,' which fits well with the model for empirical research. Sandoval-Norton & Shkedy (2019) also posit that there is a lack of introspection about the true effectiveness of ABA in supporting autistic people, which can be seen in the lack of longitudinal scientific research in this area.

A criticism of evidence-based practice has been that analysing outcomes for a large population in a clinical setting can often overlook the wider context of an individual's behaviour or presentation. The systemic factors that influence an individual are not considered when the context is excluded (Isaacs, Huang, Hernandez, & Echo-Hawk, 2005). Damian Milton, an autistic academic, argues that approaches which are based in principles of behaviourism view thoughts and emotions as operating in the same way as observable actions, without considering unobservable implications (2018). When a well-researched and reviewed approach looks only at behaviour as a result of external, observable factors then, by design, unobservable systemic factors or internal mechanisms are not considered. For example, social differences in understanding and expression, traumatic experiences, stress, emotion or even physical pain can be overlooked.

When diversity of behaviour and social communication are viewed as 'other' in evidence-based practices, these practices can become centred around 'normalising' these differences. The goal then becomes focused on eradicating the behaviours that are deemed unusual or inappropriate, rather than seeking to understand these behaviours. Conversely, when we consider diversity through a person-centred lens, we can instead look at how internal or systemic factors may have led to this presentation.

The Low Arousal Approach as Practice-based Evidence

An approach that I incorporate into my practice is the Low Arousal Approach (McDonnell, 2010), which does not have the same volume of empirical evidence base as ABA. Despite this, the Low Arousal Approach has been viewed by autistic people

and observed by practitioners as an effective approach that interprets behaviour through the dual lenses of emotion and the individual's subjective lived experience (McDonnell, 2011). With these reports, we can see the value of practice-based evidence in furthering our understanding of neurodevelopmental conditions, their presentation, and how we can support people to develop their strengths and overcome any challenges that they experience.

From my own experience, I have found that taking a person's physiological state of arousal into consideration during clinical interactions has had a significant impact upon my own practice. Rather than a 'one-size-fits-all' approach to therapeutic interventions, I can begin to tailor my interaction towards the capacity and tolerance level that the individual presents with at that time, which can change depending on both their and my own arousal level (McDonnell, 2019). This has helped to foster the unique and individual therapeutic rapport that I have with each person I support.

As a practitioner, I am cognisant of the fact that each individual I support has their own unique presentation and lived experiences. I take the time to learn about their individual strengths and challenges. When I approach my work from this perspective, I become more open to gaining insights about what is best practice for an individual, as informed by the individual themselves. By adapting our practices based on our interactions with the people we support, we allow more flexible and person-centred approaches to develop, thus making therapeutic intervention more accessible and inclusive. If researchers and practitioners work in partnership, we can identify and effect sustainable solutions that can be applied in real clinical settings (Ammerman, Smith & Calancie, 2014).

Conclusion

There is a growing debate in the area of psychology about evidence-based practice and practice-based evidence. Practitioners are sometimes criticised for failing to use empirical evidence to inform their practice, while academic researchers are often condemned for research that is deemed to be irrelevant to practice (Fox, 2003). Practice-based evidence models are a relatively new and developing method of conducting research. On the other hand, while evidence-based practice can miss the nuance of the individual experience, it is a well-established means of conducting research that can improve the practice of clinicians. Bridging the gap between practice-based evidence and evidence-based practice allows for research methods and clinical practice to evolve to represent the diversity of the human experience. As practitioners, evidence-based practice can bring efficacy to our work, but it can also overlook the unique and complex needs that an individual may present with. Person-centred practice can incorporate approaches from empirical research, while also developing approaches to achieve practice-based evidence, in order to consider the bespoke needs of the people we support. In conducting research, and applying it to clinical practice, it is important that we consider the approaches that best fit our aims as practitioners. Recognising where some approaches may fall short is an important part of this exploration. As a practitioner, I see the value in both practice-based evidence, and evidence-based practice, and how one approach can inform the other. While evidence-based practice can offer breadth and generalisability to clinical practice, practice-based evidence can give insight into the nuance of the individual or cultural contexts at play, which can guide more bespoke practices.

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