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Research Paper

"Once I'd done it once it was like writing your name": Lived experience of take-home naloxone administration by people who inject drugs

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ABSTRACT

Background: The supply of naloxone, the opioid antagonist, for peer administration ('take-home naloxone' (THN)) has been promoted as a means of preventing opioid-related deaths for over 20 years. Despite this, little is known about PWID experiences of take-home naloxone administration. The aim of this study was to advance the evidence base on THN by producing one of the first examinations of the lived-experience of THN use among PWID.

Methods: Qualitative, face to face, semi-structured interviews were undertaken at a harm reduction service with individuals known to have used take-home naloxone in an overdose situation in a large urban area in Scotland. Interpretative Phenomenological Analysis (IPA) was then applied to the data from these in-depth accounts.

Results: The primary analysis involved a total of 8 PWID (seven male, one female) known to have used take-home naloxone. This paper focuses on the two main themes concerning naloxone administration: psychological impacts of peer administration and role perceptions. In the former, the feelings participants encounter at different stages of their naloxone experience, including before, during and after use, are explored. In the latter, the concepts of role legitimacy, role adequacy, role responsibility and role support are considered.

Conclusion: This study demonstrates that responding to an overdose using take-home naloxone is complex, both practically and emotionally, for those involved. Although protocols exist, a multitude of individual, social and environmental factors shape responses in the short and longer terms. Despite these challenges, participants generally conveyed a strong sense of therapeutic commitment to using take-home naloxone in their communities.

Introduction

The supply of naloxone, the opioid antagonist, for peer administration (henceforth 'take-home naloxone' or THN) has been promoted as a means of preventing opioid-related deaths for over 20 years (Strang, Darke, Hall, Farrell, & Ali, 1996; Strang, Kelleher, Best, Mayet, & Manning, 2006; Strang, Bird, Dietze, Gerra, & McLellan, 2014).

In Scotland, a national naloxone programme is in place where those at risk of opioid overdose are typically supplied with THN via community addiction and harm reduction services (including community pharmacy) following successful completion of a brief 5–10 min training session (Bird, McAuley, Perry, & Hunter, 2016; Bird, McAuley, Munro, Hutchinson, & Taylor, 2017; McAuley et al., 2016; McAuley, Best, Taylor, Hunter, & Robertson, 2012). THN is also offered to all prisoners on release who are deemed to be at risk of opioid overdose. Core elements of the training individuals undertake prior to naloxone supply include signs and symptoms of opioid overdose, basic life support, naloxone administration, and calling an ambulance.

The bulk of research on THN to date has focussed on quantitative measures that have examined the impact of training and supply of THN on knowledge, confidence and overdose responses, before and after training, and at short term follow up intervals (Clark, Wilder, & Winstanley, 2014; Mueller, Walley, Calcaterra, Glanz, & Binswanger, 2015; McAuley, Aucott, & Matheson, 2015). Collectively, these studies highlight that people who inject drugs (PWID) internationally can successfully be trained to identify and respond to overdose events using basic life support and naloxone administration techniques.

Far fewer studies have been conducted that have focussed more on PWID's views and experiences of administering THN and the impact this has on them. To date, those which have been published mainly

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originate from North America (Heavey et al., 2018; Koester, Mueller, Raville, Langegger, & Binswanger, 2017; Lankenau et al., 2013; Sherman et al., 2008, 2009; Wagner et al., 2014; Worthington, Piper, Galea, & Rosenthal, 2006), and one from China (Bartlett, Xin, Zhang, & Huang, 2011). Collectively, these studies provide valuable early insights into the barriers and enablers to participating in THN programmes, but also to the attitudes of the individuals involved and the effects naloxone can have on them and their relationships with their peers. Related themes of security, trust and comfort emerged from different studies, and how this new naloxone role within their community had given many a sense of dignity and purpose in their life.

To our knowledge, only one such study has been published from the UK, which explored hypothetical scenarios with homeless drug users who had yet to be prescribed THN (Wright, Oldham, Francis, & Jones, 2006). For example, participants reported a willingness to take responsibility and 'save' a fellow drug user if required to do so, but it is unclear if this motivation would have translated into action with naloxone at an actual opioid-related overdose event.

Neale and Strang (2015) argue that "better understanding of opiate users' views and experience of emergency naloxone is needed to support medical care and decision-making and to inform the wider presupply of naloxone". This is particularly relevant to the UK where national naloxone programmes have been pioneered. The aim of this study was to advance the evidence base on THN by producing one of the first examinations of the lived-experience of THN among PWID in the UK.

Theoretical approach

This study adopted Interpretative Phenomenological Analysis (IPA) as its guiding methodological framework. In keeping with IPA principles, no theory is applied until the analysis is concluded (Smith, Flowers, & Larkin, 2009). The roots of IPA lie in three major areas of philosophy: phenomenology, hermeneutics and idiography (Smith, 2004).

IPA owes much to Husserl's phenomenological principles, in particular its focus on detailed exploration of lived experience (Smith, 2004; Wagstaff et al., 2014). The aim of IPA is to explore in detail an object/event of importance to an individual, in this case administration of THN by PWID.

In terms of hermeneutics and theories of interpretation, IPA acknowledges the difficulties in accessing an individual's perception of their personal world and outlines an empathic but critical interpretative process which actively involves the researcher to overcome these difficulties (Smith, 2004; Wagstaff et al., 2014). Access to perception is reliant on, but also complicated by, the researcher's own theoretical beliefs which are necessary to understand the personal world being described by the participant (Smith & Osborn, 2008). This involves both the participant and the researcher in a two-stage interpretative process: participants trying to make sense of their own world; researcher trying to make sense of the participants trying to make sense of their own world: often referred to as the 'double hermeneutic' (Smith & Osborn, 2008).

As well as being both phenomenological and interpretative, IPA is strongly idiographic in approach; each case is considered in isolation as well as in consideration of the implications each individual experience may have within the context of the whole sample (Gee, 2011; Larkin & Griffiths, 2002; Smith, 1996, 2004; Smith et al., 2009). It adopts a position that the participant provides an active insight into their world with no assumptions about objective reality or truth and where a theoretical rather than scientific generalisability is produced (Wagstaff et al., 2014).

Little is known about the lived experience of THN use among people who inject drugs. IPA is useful in this context as it allowed the research to examine in-depth the lived experience of people who had used naloxone by interpreting their accounts through analysis of the language used to make sense of that experience. Moreover, IPA helps to relay, as best as possible, what it is like to "walk in another's shoes" (Shaw, 2010).

Study methods

Fieldwork was conducted between July and October 2013 within a large urban Health Board in Scotland, UK: an area with one of the highest prevalence rates of PWID in the country.

IPA studies require small homogenous samples to allow participants scope to relay their experience in full and the researcher to fully connect with what is being described; they thus follow a purposive sampling path, akin to a series of case studies (Smith et al., 2009). Although no definitive sampling guidance for IPA studies exists, Reid and colleagues suggest a maximum of ten participants in an IPA study (Reid, Flowers, & Larkin, 2005). We therefore aimed to recruit 10 individuals who had used THN to reverse an overdose into the study. Potential participants were invited to take part in the study when attending a busy harm reduction service for routine appointments. The site was chosen due to its size and because it provided both opiate substitution therapy (OST) and injecting equipment, therefore attracting a large group of individuals with differing intensities of drug use.

The initial invitation to participate was made by a harm reduction team staff member who then directed those expressing an interest to an independent researcher (AMcA) where they were provided with a study information sheet and given the opportunity to ask questions. Potential study participants were then asked to provide written consent prior to data collection. All individuals approached agreed to take part and consented with no exceptions.

Face to face, semi-structured, in-depth interviews using a topic guide were conducted by the lead researcher (AMcA) in a private room within the service, and were audio recorded where consent was given to do so. The topic guide covered overdose history and risk, feelings about naloxone, and experience of using naloxone at an overdose event.

Participants were assured that the interviews were anonymous and confidential and that pseudonyms would be used in place of real names and places in any publications or reports. Interviews lasted between 30 and 70 min and participants were given a £10 shopping voucher to compensate them for their time. Appropriate ethical and management approvals were granted from the NHS West of Scotland Research Ethics Service (WoSRES), the local NHS Research and Development department and the University of the West of Scotland.

Analysis

All interviews were digitally recorded and transcribed verbatim by the lead researcher (AMcA) with the exception of one who refused to consent to recording and only gave permission for handwritten notes to be taken. Anonymised transcriptions were entered into NVIVO (version 10) to facilitate analysis. Analysis was conducted by the lead researcher (AMcA) and reviewed by the research team (AM, AT). Differences in interpretation were discussed in detail at regular research team meetings and resolved by consensus.

The IPA analysis was conducted in four stages in accordance with Smith and Osborn (2008): (1) Identification of initial themes; (2) connecting themes; (3) tabling of themes; (4) analysing further cases. During the initial stage, notes are taken on any points of interest or significance; these range from descriptive notes (e.g. objects, events), to linguistic comments (e.g. repetition, hesitancy, metaphor), to conceptual observations where the researcher begins to interpret and question the data (Smith et al., 2009). Ultimately, the analysis should generate an extended narrative which illustrates how the researcher thinks the participant is thinking (Smith et al., 2009). It is this interpretative narrative, introducing and analysing experiential themes, which Smith (2011) argues is the key difference between IPA and other thematic-based approaches and yields an analytical account which is