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Evidence and examples from the Netherlands

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Experiential knowledge as a resource for coping with uncertainty: evidence and examples from the Netherlands

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In this article, we examine how experiential knowledge is used in areas such as mental health care and youth policy and how it relates to the dominant form of knowledge that underpins these policy areas, ‘expert knowledge’. Experiential knowledge is sometimes considered a resource that helps people in vulnerable situations respond to uncertain futures. Although frequently undervalued, experiential knowledge is involved in multifaceted responses to situations imbued with uncertainty. In this article, we examine the nature of experiential knowledge as a resource and develop a typology of experiential knowledge drawing on existing studies. Experiential knowledge is not merely ‘lay beliefs and fallacies’ that holders of expert knowledge should be aware of so that they can better implement top-down strategies; it reflects lived experiences that are difficult for outsiders to capture. In the Netherlands, the rise of lived experience as a resource for intervention was born through the critique of the hegemonic power of ‘expert knowledge’ and as policymakers recognised the potential contribution of ‘experiential experts’ in shaping responses to situations characterised by high uncertainty. In such situations policymakers can draw on insights into the experience of usually silent stakeholders: people deemed at risk. In this article, we also highlight tensions related to these particular multifaceted responses, suggesting that experiential knowledge is viewed with ambivalence by some other stakeholders.

Keywords: risk; experiential knowledge; mental health; peer work; self-help; vulnerability; youth at risk

Introduction

Policymakers and care professionals involved in mental health care and youth policy often have to deal with and respond to situations that are imbued with uncertainty due to an accumulation of multifaceted problems. In these situations there is frequently a multiplicity of actors who have different ways of assessing, analysing and responding to uncertainty, even though these assessments, analyses and responses are meant to be compatible and complementary. As a result, responses to such complex problems tend to resemble a ‘bricolage’ (Horlick-Jones, Walls, & Kitzinger, 2007, drawing upon Irwin & Wynee, 1996 and Levi-Strauss, 1966). In this article we explore the ways in which such bricolages draw upon non-expert knowledge, such as experiential knowledge, and how this experiential knowledge relates to other forms of knowledge, especially ‘expert knowledge’. As a complement to research on the relevance of tacit knowledge (Klein, 1998; 2008; Zinn, 2008; 2015), we focus on and develop an understanding of the nature of experiential knowledge as a resource for real-life responses to risk and uncertainty.

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in situations of high complexity. We need to develop an understanding of the nature of ‘lay knowledge’ (Popay & Williams, 1996) beyond the fallacious lay beliefs that some holders of professional knowledge accept to consider in their practice and how lay people know about risk ‘otherwise’ – due to their own experience of exposure to risk and uncertainty and how such elements of experiential knowledge are actually recognised in policymaking and practice. We examine how experiential knowledge compares to other sources of knowledge deemed reliable, such as expert knowledge, and what individuals who experience the challenge of uncertain situations such as mental health learn and how they use this ‘to understand and take a view on [uncertainty]’ (Horlick-Jones et al., 2007, p. 97).

Expert and experiential knowledge

In contemporary high-income countries some individuals and social groups are at a ‘higher risk of risks’ (Frohlich & Potvin, 2008, p. 218) – of experiencing mental health problems, addiction and criminality (often all three) and living in circumstances in which they do not have adequate protection or a ‘safety net’. Such individuals are vulnerable, for example to ill-health and social isolation. The dominant social response is provided by established professional groups, such as teachers, general practitioners or social workers, who use their ‘expert knowledge’ to ‘treat’ those in these vulnerable situations. However, it is not clear whether these experts with their expert knowledge have provided effective interventions. Some commentators (Morin, 1986) have argued that these problems can only be addressed by using different sources of knowledge, especially the experiential or lay knowledge, which those experiencing these problems have built up over time.

Though lay or experiential knowledge is often undervalued, especially in English-speaking countries (Beresford, 2000; Popay & Williams, 1996; Rothe, 2016; Walklate & Mythen, 2011), Horlick-Jones and his colleagues (2007) have observed that much of the policy-related literature accords such forms of knowledge an important role in policymaking and everyday practice.

Our discussion of the substance and robustness of experiential knowledge builds upon debates about the distribution of knowledge at stake in strategies meant to cope with risk and uncertainty. We will argue that the frequently observed contrast between ‘lay knowledge’ and ‘expert knowledge’ does not help much since in contexts of high uncertainty, such as those that are the focus of this article, as so-called ‘expert knowledge’ is often scattered and divided. We will argue that a consideration of ‘wrong knowledge’ can provide insight, as it questions the intrinsic value of experiential knowledge. However, to allow a thorough analysis of what aspects of experiential knowledge have to be appreciated, we suggest looking beyond the remit of public health and crime research and turning to studies of self-help groups, so as to set up a suitable schema. ‘Self-help’ and ‘peer work’ studies have the potential to provide insights into the substance of experiential knowledge as resource for social action and about how this connects to expert knowledge.

To provide a more tangible context for our analysis of experiential knowledge as a resource to respond to situations imbued with uncertainty, we draw on a number of cases within the Netherlands. The ‘experiential expertise’ (this is a translation of ervaringsdeskundigheid, the term most widely used in the Netherlands) of people who have been living through difficult circumstances has frequently been drawn upon within institution-led strategies that aim to assist people living through similar circumstances. In this article we discuss the growth in recognition of ‘experiential expertise’ in the Netherlands. We will show how this type of knowing has increasingly been seen as an indispensable...
ingredient of responses to new and/or complex social issues, mainly in the area of mental health. This enables us to specify three core dimensions of experiential knowledge as a resource for action. Building on a discussion of the recent development of experiential expertise as a distinct occupation in the mental health care sector and in youth-related policy, we highlight additional dimensions of experiential knowledge as a resource for action.

We also explore the articulation of how ‘knowing otherwise’ is applied in practice, especially in relation to other forms of knowledge. Here we draw on examples from both mental health care and youth work, showing that the recognition process is not absolute, with different modes and levels of recognition depending on which dimensions of experiential knowledge are considered. We note that not all elements of experiential knowledge are equally recognised, with experiential knowledge viewed with ambivalence by various stakeholders.

Making sense of the situation of those at risk: from public health and criminology to self-help studies

In situations characterised by increased uncertainty due to the exposure of already-vulnerable groups to an accumulation of problems, the relevance of the distinction between ‘lay knowledge’ and ‘expert knowledge’ is open to question. The complexity of the problems means that ‘expert knowledge’ alone is inadequate. Following Walklate and Mythen (2011) and an exploration of the variety of knowledge(s) involved in responses to social issues such as sexual health and substance use among adolescents in Canada (Baillargeau, 2016), we argue that it is possible to identify three types of knowledge: scientific, clinical and experiential knowledge.

Building upon scattered knowledge

Making sense of uncertainty often calls for a variety of ‘truths’, stemming from a diversity of viewpoints and modes of reasoning. In that regard, ‘expert knowledge’ has been commonly contrasted to ‘lay knowledge’. This dichotomy is relevant for discussing the distribution of knowledge and power differentials in certain policy areas. Expert knowledge is often more valued and given higher standing than lay knowledge (Popay & Williams, 1996; Wynne, 1996). To provide clarification of and grounds for a thorough analysis of the distribution of knowledge, we suggest a different framework, one that differentiates among scientific, clinical and experiential knowledge and their application to social issues (Baillargeau, 2016; Walklate & Mythen, 2011).

While attempting to interpret uncertainty, ‘experts’ often resort to scientific knowledge, such as epidemiology that is based on statistical analysis of past phenomena. For example, in an attempt to understand the causes of crime, researchers have focused on issues such as criminal careers, searching for recurrent features in individuals and their proximate environments (family, neighbours, friends – Farrington, 2007). Such statistical data is used to inform focused crime prevention strategies (Knepper, 2007; Crawford, 2009). However, making sense of social issues in contexts of uncertainty also involves clinical knowledge, developed by professionals who are engaged in everyday practice that relates to what is framed as problematic. This knowledge combines scientific knowledge with practical experience and is rooted in professional education, training and professional experience. Practical knowledge is a key element in clinical knowledge and clinicians build this up through face-to-face observations, screening and evaluation of persons facing social issues or deemed at risk. Based on observations of medical physicians, psychiatrists and their service-users, Castel (1983) argued that clinicians are in a ‘personalised’
relationship’ with service-users, which provides the basis of their practical knowledge. Because clinical knowledge is situated knowledge, grounded in face-to-face interactions, it draws upon a wide range of information including, as we have noted, scientific knowledge in order to create an ‘understanding of particulars to be integrated with the understanding of universals’ (Malterud, 2001, p. 398, see also; Benner, 2001). Both scientific knowledge and clinical knowledge have the legitimacy of expert knowledge, and they overlap to some degree. However, they both have distinct characteristics, and they often compete with each other. This is exemplified by the tensions generated by the development of predictive techniques, informed by probabilistic research, in areas such as child protection, where clinical risk assessment has long been dominant (Hebberecht & Baillergeau, 2012; Parton, 2011). Thus, ‘expert knowledge’ is hardly uniform, let alone unquestioned. Analyses of responses to situations imbued with uncertainty can benefit from the ability to account for the dynamics of truths that nurture the views of professional experts by distinguishing clinical and scientific knowledge.

In contrast to scientific and clinical knowledge, ‘lay knowledge’ is grounded in the experiences of the people facing the challenging problems of everyday life. Building on direct experience of illness and/or disability but also a range of other social conditions such as unemployment, substance use, school truancy and so on, ‘lay’ or ‘experiential knowledge’ is a type of knowledge that has the potential to enhance the understanding of the nature, causes and most effective responses to social problems.

‘Wrong knowledge’ versus ‘knowing otherwise’

Prior (2003) has discussed the nature of experiential knowledge as a resource for action. Drawing upon health research, he highlighted the recognition of ‘lay knowledge’, increasingly presented as a useful, alternative source of knowledge with respect to health issues. However, Prior advocated restricting experiential knowledge to the knowledge of a condition, claiming further that lay knowledge is not reliable because it can be ‘plain wrong about the causes, course and management of common forms of disease and illness’ (2003, p. 45). In this view, experiential knowledge should be seen as a helpful resource as long as it is understood as ‘wrong knowledge’ (or ‘urban myths’) that, paradoxically, may help improve the quality of interventions. It is indeed useful for clinicians to be aware of young people’s fallacious lay beliefs about sexually transmissible illnesses to better provide and communicate preventive care. This understanding of experiential knowledge as ‘wrong knowledge’ is certainly relevant (especially regarding the causes of some well-known illnesses) and has proved helpful for interventions inhibited by particular understandings, to offer better protection to some risk groups (for instance regarding HIV/AIDS in the 1980s). In this sense, ‘wrong knowledge’ is not fiction, and needs to be known by professionals and to be counteracted for the sake of public health.

However, experiential knowledge is far more than ‘wrong knowledge’. There are issues for which uncertainty is high, such as the role that being overweight plays in various health conditions (Tylka et al., 2014), or the causes of crime (Hebberecht & Baillergeau, 2012). In such cases, it can be difficult to settle whether or not expert knowledge is significantly more reliable than lay knowledge. Others have an even more positive view of experiential knowledge. In particular, Walklate and Mythen (2011) have argued, following feminist informed work, that the intimate experience of living with what is framed as domestic violence provides, as a form of ‘knowing otherwise’, a genuine added value for domestic violence risk assessment. If this is the case, then inherent and structural factors do not provide an adequate explanation of domestic
violence and need to be complemented by knowledge grounded in the experiential nature of vulnerability (Walklate, 2011, p. 187). As such, it is not ‘wrong knowledge’ but genuine and robust knowledge deriving from experience that can become a specific resource for the development of self-resilience in situations of adversity. So, even if experiential knowledge happens to consist of ‘wrong knowledge’ and urban myths, experiential knowledge is a way of ‘knowing otherwise’ rather than a form of the ‘wrong knowledge’. Acknowledging ‘knowing otherwise’ entails taking ‘wrong knowledge’ to be neither totally fictional nor wholly embracing experiential knowledge as a resource for action.

Contrasting ‘wrong knowledge’ with ‘knowing otherwise’ allows researchers of uncertainty to question the nature of judgements regarding the situations of those considered to be at risk by those involved in supporting them. It is possible that the interest of frontline professionals in clients’ experiential knowledge of service-users and how this affects their interventions is restricted to gain information on the ‘wrong knowledge’ that would hamper their interventions. If, on the other hand, frontline professionals are interested in ‘knowing otherwise’ in specific contexts, then they need to consider how this alternative knowledge can be accessed. Whilst ‘wrong knowledge’ can be judged wrong by comparing it with expert knowledge, it is more difficult to evaluate experiential knowledge as it is different from and cannot be evaluated in terms of expert knowledge. When discussing domestic violence, Walklate and Mythen (2011) situate the basis of ‘knowing otherwise’ within intuition, as it relates to

family history of abuse, gender role socialisation, attitudes toward violence of the immediate and extended social network, various characteristics of the abuse and abusive partner’ (2011, p. 108, drawing upon Smith, 2010, p. 27).

Thus, intuition is the basis of practical knowledge, which is developed through personal experience and internalised so that it seems to the person using it ‘naturally’ relevant to judge and deal with problematic situations. In Zinn’s terms it is ‘tacit knowledge and pre-conscious awareness of reality’ (Reber, 1995; 2008, p. 443, drawing on), while Horlick-Jones sees it as ‘situated rationality’ that is part of decision-making in risky situations (2005; – see also Douglas, 1992; Bloor, 1995). It is clear that such intuition is a personal basis of experiential knowledge and is shaped by individuals’ experiences and this practical knowledge is applied to make sense of and take action in new situations (see also Klein, 2008). However, to explore the potential value of such knowledge, it is important to move beyond mere recognition and examine areas in which experiential knowledge of those at risk has been acknowledged as having an intrinsic value. In the next section, we will consider one such area – self-help.

The substance of ‘knowing otherwise’

In the context of the rise of self-help groups in the 1960s, experiential knowledge has been advocated as ‘truth based on personal experience with a phenomenon’ (Borkman, 1976, p. 445). It has also been deemed robust enough to enable holders of such knowledge to help peers faced with a similar ‘phenomenon’. For example, Borkman noted that in the United States for a wide range of ‘conditions’ there were self help groups:

In addition to such well-known older groups as Alcoholic Anonymous, Synanon, Overeaters Anonymous, Gamblers Anonymous and Recovery Inc., self-help groups for patterns who
abuse their children, stutters, sex offenders, divorces Catholics, adoptees, priests and nuns leaving religious life, and alienated people, among others, have developed. (Borkman, 1976, p. 454, note 1)

In such groups, experiential knowledge has become an acknowledged resource that enables and empowers action aimed at others. Likewise, in ‘self-help’ (Shiner, 1999), experiential knowledge is assumed to place ‘peers’, individuals who have had experience of what is socially framed as problematic (disability, substance misuse, sex work and so on), in a favoured position to help fellow peers going through similar problematic situations. Such peer help becomes a quasi-occupation when undertaken regularly and forms the interface between the self-help group, as a social movement, and the group provision of social intervention and therapy (Bellot et al, 2006; Godrie, 2015; Llobet, Baillergeau, & Thirot, 2012). Both groups – self-help and individual peer work – are grounded in the belief that the experiential knowledge that members of the group have developed through their experiences of living with and dealing with the specific condition provide an important and effective resource for providing help, support and intervention. Yet much of this collective experiential knowledge is different from and cannot be validated by the knowledge used by experts (Munn-Giddings & McVicar, 2007). As such, self-help and peer work may aid understandings of the process through which personal experiences and characteristics develop and crystallise into knowledge that can be used to help others going through similar experiences. We explore these issues further through two illuminating cases from the Netherlands.

Experiential knowledge as a resource for action – self-help groups versus health care and youth work

Although there has been very little research on Dutch peer work and self-help, they have – in the early twenty-first century – become central to many institution-led responses to social problems. In the 1960s they developed very much outside of the public sector, but they have increasingly become mainstream and accepted as an important component of the welfare system by policymakers. In addition to providing insight into how experiential knowledge relates to various takes on expert knowledge of situations characterised by high uncertainty, our analysis of the Dutch cases of peer work and self-help will provide a better understanding of experiential knowledge beyond ‘wrong knowledge’.

One of the first policy areas in the Netherlands in which policymakers recognised the potential of experiential knowledge as a resource for intervention was mental health care (including drug addiction care/rehabilitation). Other contexts included homelessness, disability, child neglect (Van Regenmortel, 2009; Van Regenmortel, Demwyer, & Vandenbempt, 1999) and poverty (Hilhorst & Van der Lans, 2015). In the 1990s, state agencies started to employ ‘experiential experts’ to support people with a mental health condition. The involvement of such experiential experts was considered as a way of moving beyond ‘symptom’ management to full recovery where those affected by mental illness could find a fulfilling role and life within society (Anthony, 1993; Plooy, 2006; Van Regenmortel, 2009).

By 2009, 250 ervaringswerkers or experiential experts were employed and working in the Dutch mental health-care sector, many of whom had come from socially disadvantaged backgrounds (Van Regenmortel, 2009). At the same time, there was an increase in the number of training programmes for experiential experts in Dutch vocational schools and these schools encouraged the development of a recognisable occupation of
experiential expert (Van der Heijden, Van Noppen, & Van Lanen, 2011). In 2012, a Dutch occupational association of ‘experiential experts’ was established. One of the functions of this association was to advocate the recognition of the function and the profession of experiential experts. Despite these impressive signs of the formalisation of experiential knowledge as a resource for intervention, some policymakers and frontline professionals have had reservations about the development of ‘experiential experts’.

The notion of experiential expertise originated in the early 1980s, following criticism of the hegemonic power of professionals (Duyvendak, 1999). This critique was particularly evident in mental health care (Tonkens, 1999). Dutch critics such as Achterhuis (1980) drew on critiques of professional power in America, for example Freire (1970) and Illich (1976). These critics of established professionals saw technologies and skills based on individual and group experiences, in Illich’s terms, vernacular technologies, as an alternative to professional expertise and a way forward. They argued that such technologies and knowledge provided a more effective way of dealing with issues. They also saw it as a way of empowering users as experiential experts could share their experiences and backgrounds and did not claim to be superior or sit in judgement. Experiential experts could facilitate a democratisation of care (Tonkens, 1999). In psychiatric care, some service-users became knowledge bearers (dragers van kennis) (Plooy, 2009, p. 22), as part of the clients’ movement of those engaged in self-help groups.

Throughout the 1980s and the 1990s, the status of experiential expert and the knowledge they used grew in the context of these flourishing self-help movements. This sometimes resulted in the establishment of care provisions outside of institutions, which primarily relied on self-help, with a limited role for professionals. Service-user organisations advocated for recovery programmes in which former service-users played a key role (Boertien, Van Bakel, & Van Weaghel, 2012). However, the impact of experiential expertise also permeated established services and professional practice in which the experiences of service-users become at least as important as the knowledge of the professional not only in the ‘diagnosis’ of problems, but also in the ‘treatment’ of the ‘condition’.

The influence of experiential expertise was evident in other areas of health policy. For example, as HIV/AIDS became a major challenge in the 1980s, new services developed both to treat those affected and to minimise the spread of the disease. In the Netherlands, individuals who experienced the disease had a strong influence on the design and development of treatment services. The main ‘at-risk’ groups, especially gay men, were actively involved in the design of prevention campaigns. As a result, both treatment facilities and prevention campaigns have a distinctive Dutch character (see Duyvendak, 1997; Duyvendak & Koopmans, 1991).

Initially there were serious tensions between Dutch self-help and peer work based on experiential knowledge and the profession-based services using expert/medical knowledge. As in the United States (Borkman, 1976), Canada (Baillergeau, 2008; Fontaine & Richard, 1997) and many other high income countries, self-help and peer work developed mostly in gaps left by institutional care. Such gaps existed because professional services did not address some issues or because those receiving the services did not consider them appropriate or adequate. As time passed, self-help groups moved out of the gaps and into the mainstream to influence the quality of services received by most service-users. There were two prongs in this move into the mainstream: information and training for ‘regular’ health-care professionals based on experiential knowledge and the direct application of such knowledge by the new occupation of experiential experts. These developments became the foundation for the current development of experiential expertise as an
intervention resource in the health and social sectors. In this movement, experiential knowledge is advocated as an intrinsic, alternative source of knowledge of illness and risk, in line with Walklate and Mythen’s understanding of ‘knowing otherwise’ (2011). In so doing, policymakers and service providers acknowledge the limitations of expert knowledge in situations characterised by high complexity (Horlick-Jones, 2005) and responses to the situations are adapted so as to take into account a variety of knowledge forms held by a variety of actors – just as in some models of ‘risk governance’ (Renn, Klinke, & Van Asselt, 2011).

The development of Dutch self-help groups highlights three main arguments for valuing experiential knowledge, featuring three dimensions of experiential knowledge as a resource for action. These three dimensions are also reflected in Plooy’s analysis of the development of experiential expertise in the area of mental health care (2009, p. 21). These are:

- **Survivors’ experience.** The experience of having lived through a condition should provide a survivor with more insight and knowledge about that condition than those who have never experienced such a condition themselves. For example, people who suspect they have been infected with HIV/AIDS have to go for testing and deal with the consequences of their diagnosis (Duyvendak, 1997);
- **Experience of care institutions and/or treatment.** This should enhance an individual’s capacity to make judgements about these institutions and treatments. For example, after having been in contact with a collection of professionals, mental health service-users have a distinctive view of mental health care (Tonkens, 1999);
- **Experience of labelling and associated stigma.** Those who have undergone diagnosis and treatment are more likely to be aware of the stigma associated with the diagnostic label and with the treatment. For example, people labelled as mental ill experience the damage that this label does to their social identity and opportunities (Plooy, 2009).

The three dimensions also echo Godrie’s (2015) grounded analysis of peer work in mental health in Canada. These three features, however, are not exhaustive. More issues can be discerned when we look at situations where ‘lay’ experiences are translated into specific occupations, reflecting another step in the recognition of experiential knowledge of situations imbued with uncertainty.

In the 1990s in the Netherlands, the role of the ‘bearers’ of experiential knowledge evolved from simply giving advice to frontline professionals to actively engaging in working with clients (Plooy, 2009). In the early twenty-first century experiential expertise was recognised and actively engaged in other fields, for example ‘youth at risk’ – that is young people who were likely to or had left school early without qualifications. These young people were in danger of social isolation, for example they had lower chances of getting work than their peers who stayed on at school, were more likely to engage in activities such as drug or alcohol misuse and crime and often experienced psychological problems such as low self-esteem due to their problematic experiences of school and their experiences of (repeated) failure. From the mid-2000s, youth policy and practice increasingly turned to mentoring and/or coaching provided by young adults who had succeeded in spite of coming from the same social backgrounds as their at-risk peers. The aim of this peer-mentoring was to enable these at-risk young people to develop their talents and participate in society (Baillergeau, 2012; Baillergeau, Duyvendak, Hoijtinck, Llobet, & Thirot, 2009; Van Hoorik, 2011). Alongside one-to-one mentoring, there is also group
work in which rolmodellen (role models) young professionals who have successfully overcome personal troubles are invited to talk to young people to spell out the danger of crime and how they avoided or dealt with them. The aim is to offer young people in their formative period inspiration from ‘positive’ role models (De Jong, 2013) to counteract the potential influence of ‘negative role models’, such as elder siblings or friends who are engaged in crime.

While role models in the usual sense of the term are spontaneously selected by young people themselves (Harter, 2006), the idea here is to prompt young people towards ‘role models’ that embody socially accepted roles (the capacity to sustain one’s life in a law-abiding fashion). Even though these role models may be different in some senses from the young people they target, a key point is that the professional role models share many features with the targeted young people, that is, they have a similar social background. In the context, the experiential knowledge is embodied by community-based role models, whose lived experience is a key resource. As such, they are meant to be not only exemplary figures but also a sort of mentor, providing support and help to the targeted young people.

The expected profile of community-based role models represents the three dimensions of experiential knowledge we have highlighted. They have undergone the same experiences as their target group, most obviously living in a disadvantaged neighbourhood; many of them have been through youth-care institutions or job experience programmes; and many of them have a personal experience of belonging to a social group stigmatised by race or religion, which tends to exclude them from mainstream opportunities such as work. However, the expected profile of experiential experts exemplifies two additional features, echoing those highlighted by Godrie in the case of peer workers (2015). While approaching young people at risk regarding a mentorship programme (Baillergeau et al., 2009), community-based mentors make use of their experience of having discovered coping strategies within oneself. They have also experienced success in using such strategies, typically at the end of long and arduous pathways. In the language of mental health care, they have experience of recovery. In the case of mental health care, former service-users’ recovery indicates that they have learnt to distinguish what within prescribed treatments worked for them and what did not and have found a successful pathway to recovery and confirmation of their coping strategies. In the area of youth work, rolmodellen have been through all kinds of work experience projects, internships, failed attempts to find a job on the regular labour market and have eventually experienced success, by getting a degree, finding a job or creating one’s own business such as a kickboxing school or a music band. Such evidence of success is an essential qualification for becoming a rolmodel and being enrolled in mentoring projects.

Godrie (2015) has identified two additional dimensions of experiential knowledge that may be understood as ranking beyond ‘wrong knowledge’. On the one hand, experiential knowledge may stem from the experience of connected issues, such as, in the case of some mental health service-users, the experience of addiction. These connected issues contribute to making situations more complex and lead to service-users having to cope with multiple strategies, sometimes requiring them to consult with a diversity of professionals, who are not necessarily aware of the existence of each other. Similarly, in the case of youth at risk, an issue that is potentially connected to school truancy is that young people spend more time in public space and are exposed to criminal gangs. On the other hand, Godrie (2015) highlighted the experience of alternative resources, such as homeless shelters, for those who have had bad experiences in the usual care institutions. Such experiences make people aware of the diversity of available responses and the diversity of
approaches, for which they can compare advantages and shortcomings. Community-based rolmodellen have similar practical knowledge. This is the case, for example, when guidance provided by regular educational institutions proves unsuccessful, and young people turn to non-profit organisations offering alternative mentoring programmes. Thus, these two additional dimensions are also relevant.

There is one more dimension of ‘knowing otherwise’ that stems from the experience of advocacy. Service-users who commit themselves to a service-user organisation have the opportunity to learn from their work as advocate and the voice of experience. Mentoring projects can also provide opportunities for young people identified ‘at risk’ to talk to power, to those who can influence the allocation of resources, for example local politicians about issues such as poor prospects on the local labour market or ethnic profiling. They can experience a form of empowerment that comes through collective action and by making themselves heard by outsiders.

Based on our observations (Baillergeau et al., 2009) and those of Plooy (2009) and Godrie (2015) of experiential experts, we can highlight eight potential features of experiential knowledge understood as ‘knowing otherwise’ or, in other words, what experiential knowledge is likely to be based on when it is considered a resource for action deemed more valuable than ‘wrong knowledge’. Experiential experts gain knowledge through having different experiences of their condition and its treatment. These can include some or all of the following:

- The experience of having been through a condition (physical, mental or social, for instance school dropout)
- The experience of handling multiple, concurrent and connected problems/difficulties (for instance addiction when facing mental illness)
- The experience of having lived through care institutions and/or treatment (for instance a psychiatric hospital)
- The experience of alternative or complementary settings (for instance homeless shelters, especially if regular care institutions were experienced negatively)
- The experience of social consequences of a condition framed as problematic and/or of related treatment (for instance stigma)
- The experience of discovering coping strategies within oneself
- The experience of recovery itself
- The experience of advocacy.

Such sources of knowledge are situation specific and reflect the diversity of personal experiences that people who are expected to act as peer workers can use.

Having identified the sources of knowledge in the next section we move on to consider how the knowledge gained is valued compared with other forms of knowledge, in the fields of mental health and youth care in the Netherlands.

‘Knowing otherwise’ as a practical resource for intervention

Though experiential experts operate in a wide range of settings in the Netherlands and the value that they add to social interventions has been repeatedly advocated, it is surprising that researchers in the Netherlands have not undertaken more research on this type of expertise. There are, however, exceptions; some researchers have examined practices involving peer workers and/or made statements regarding the added value of their contributions.
In the field of mental health, Van Vugt and colleagues (2012) have researched the contribution of experiential experts enrolled in outpatient clinics for clients with severe mental illness, notably homeless people. They examined how former service-users were hired and invited to join (recovery-oriented) professional teams, collaborating on a daily basis with professionals such as medical doctors and nurses (see also Van Der Heijden et al., 2011).

Similarly in youth-oriented crime prevention, Sieckelinck and colleagues (2013) as well as De Jong (2013) analysed youth practices involving people regarded as rolmodellen or positive role models and hired as mentors of young people enrolled in some professional-led projects for social (re)inclusion. The mentors were either identified by the young persons-at-risk or sought out by professionals. In the latter case, professionals selected and supported the mentors and connected them with all relevant participants (De Jong, 2013, p. 48) including school attendance officers, police officers and job guidance counsellors. Experiential experts were also invited to take part in collaborative work to complement the input of otherwise trained professionals, especially where conventional social interventions had not been able to help specific young people.

In this section we consider the insights these studies provided into experiential experts and expertise. In the case of mental health services, we will include a review of the professional literature addressing experiential expertise. In the case of youth work, we also draw on field observations we carried out in several parts of Amsterdam between 2008 and 2015. These observations primarily consist of in-depth interviews with experiential experts or their partners, commissioners or target groups (Baillergeau, Duyvendak, & Cuijpers, 2014; Baillergeau et al., 2009). We start by reviewing the evidence of the recognition of experiential knowledge in the two areas. We then discuss what we learn from observing the two areas. Here, we focus on the position of experiential knowledge within multifaceted responses and how experiential knowledge is articulated as scientific and clinical knowledge of situations imbued with uncertainty. Finally, we will use our multidimensional schema to discuss the different modes and levels of recognition of experiential knowledge within the multifaceted responses.

The recognition of experiential knowledge

In their longitudinal study of ‘assertive community treatment programs’ in various Dutch cities, Van Vugt and colleagues (2012, p. 477) found a statistically significant positive correlation between the enrolment of experiential experts who were known as ‘consumer-providers’ and service-user recovery. They found that, thanks to their experience of recovery, consumer-providers improved service-users’ acceptance of their illness and helped their recovery. Besides positively influencing users’ attitudes towards available care and treatment, consumer-providers seemed to have a positive impact on professionals in the care team by increasing their awareness of service-users’ suffering (Van Vugt et al., 2012, p. 480).

In their study of youth-focused crime prevention projects in Amsterdam, De Jong (2013) undertook a qualitative analysis of the commitment of mentors. He found that the main contribution of community-based mentors was based on two factors: they provided protection against the environmental factors contributing to crime such as the influence of negative role models and peer pressure. Having the experience of resisting such pressures, mentors were able to provide practical and moral support to young people at risk (De Jong, 2013, p. 43), for example helping at-risk young people find alternatives to crime-based income. In addition, mentors could help at-risk young people bridge the ‘system
world’ of conventional care and the ‘life world’ of their everyday lives (De Jong, 2013, p. 44 – drawing on the Habermasian concepts as is commonly done in the area of experiential expertise – see also Hilhorst & Van Der Lans, 2015).

In our own research, a qualitative study of youth policy in Amsterdam, we asked a variety of professionals working in youth policy and practice (Baillergeau et al., 2014) to tell us how they learnt about the needs of disadvantaged young people. Some participants in our study, unsurprisingly, talked about the statistically grounded categories designed to inform social/youth policy (reflected in policy documents and/or ‘grey’ literature). Yet, many of the participants in the study coming from various backgrounds (local policy officers and frontline youth professionals) also referred to (explicitly or implicitly) their own professional knowledge, rooted in years of experience in working with young people, noting that it was important to look at the question behind the question. They observed that when young people came to professionals, they talked about particular issues such as financial problems. But upon probing, many participants noted that the experience of experiential experts enabled them identify the question(s) behind the question, using their own experiences of living in the area where the at-risk young people lived and having confronted similar challenges. Thus the participants in our study argued that the intimate experience of social problems was a reliable source of knowledge for policy and practice relating to the conditions of young people at risk.

Drawing on studies of self-help in substance-use-prevention projects, Shiner (1999) looked at the roles endorsed by peers and found that self-help can take the form of peer delivery, in which peer educators pass a message on to a target group, or peer development, in which they work with a peer group (see also Bellot et al., 2010). In the Dutch mental health-care sector and youth policy and practice, both peer delivery and peer development approaches are evident. Van Regenmortel et al., (1999) and Van Regenmortel (2009) has advocated peer development as a way of using experiential expertise to create user empowerment. There is a third way in which experiential experts can contribute to services. They can inform local policymakers and practitioners, as exemplified in the case of youth policy. This role of experiential knowledge is acknowledged beyond the community of experiential experts, most notably by local policy officers.

**Experiential knowledge as part of multifaceted responses**

Granting some holders of experiential knowledge official recognition challenges the very notions of expert knowledge and expertise. However, in current practice, it is possible to see different ways in which such knowledge is formalised. In the case of the Dutch mental health care, ‘knowing otherwise’ has become part of practice as mental health service-users are encouraged to reflect on their own history of illness and treatment by comparing with those of others (Plooy, 2009), often through peer group activities. This reflection and reworking process is complemented by professional training. This underpins the development of partnership in which experiential experts become a resource for health professionals who are trying to manage persistently difficult cases for whom conventional forms of treatment have not worked. At the end of the process, professionals are helped to engage with service-users in such a way that makes it possible to take better account of their personal histories, including positive as well as negative experiences of care (Plooy, 2006; 2009; Van Regenmortel, 2009; Van der Heijden et al., 2011).

As opposed to ‘regular’ health workers who are most often trained to focus on the condition of service-users, experiential experts are able to consider how service-users’
conditions interact with certain circumstances. Yet, the position of experiential workers is
different from that of client experience, in the sense that experiential expertise includes a
capacity to analyse and reflect on one’s own experience, possibly by taking into account
the experience of others (Van Regenmortel, 2009; drawing upon Plooy, 2006). In the case
of dealing with youth at risk, ‘knowing otherwise’ turns into occupational practice
through mentoring (Newburn & Shiner, 2006), in which a (formally or informally
appointed) mentor provides young people in difficult circumstances with both a ‘mirror’
(a chance to reflect on their personal history, abilities and ambitions) and ‘opportunities’
(chances to change their position for the better, for instance by enrolling in a club or a
project). In doing so, experiential knowledge of the area where young people live provides
community-based mentors with a capacity to grasp a sizeable share of what brings young
people to be at-risk alongside forms of coping amid such difficulties.

The role of experiential experts varies across circumstances; their relationships with
other stakeholders need to be negotiated and will also vary. In mental health care,
experiential experts are often invited to take part in group work in which they are
supposed to complement and fill the gaps of medical/psychiatric knowledge so as to
secure long-term/sustainable recovery (Plooy, 2009). In this case, experiential knowledge
appears to complement scientific knowledge and clinical knowledge. However, as Kroet
(2015) has noted, there can be tension in these relationships and some experiential experts
operating in the Dutch psychiatric world feel ‘like an ant [trying to push] a rock’ (Kroet,
2015, p.1).

In the case of youth at risk, experiential experts carry out multifaceted mentoring in
which they are the key, and often only, players. Mentors interact with other stakeholders
such as policy officers, teachers and police officers, but the follow-up depends on them to
a greater extent than in mental health care. These responses chiefly draw upon experiential
knowledge, which is officially recognised, and also upon a minor degree of clinical
knowledge, accumulated over time. As key players, they are locally seen as a ‘bridging
figure’ (Sieckelinck et al., 2013; Van Gemert, 2015).

While experiential experts appear to have a clear role in some services, this does not
mean that incorporation of experiential experts takes place without tensions. This is
apparent in both fields, especially in places where experiential experts tend to also draw
upon a degree of clinical knowledge. Whilst experiential experts in mental health care
successfully complement medical expertise with out-of-reach information regarding the
experience of service-users and hidden contextual factors, there is less self-evident
collaboration with social workers intervening in the lives of mental health service-users.
The mismatch seems to be partly due to a lack of clear distinction between the forms of
knowledge applied by each group of workers. Through their clinical work experience,
social workers have learned a lot about their clients’ perspectives of their conditions as
well as their experiences of treatment (Weerman, 2009).

Experiential experts, because of their training and their experience as peer workers
(Kroet, 2015), can access some clinical knowledge and even some scientific knowledge.
Thanks to their educational training, social workers have more access to scientific knowl-
edge than peer workers, but this is less recognised in the current policy context. Regarding
youth crime prevention, the main difference between community-based mentors and
youth workers is that youth workers hold a degree and commonly follow a more
recognised methodology (to which the former do not grant much value (Baillergeau
et al., 2009; De Jong, 2013)). However, in the Netherlands youth workers’ training and
methodology are neither distinctive nor are they restricted to youth workers, so the
differences between the mentors and youth workers can be minimal.
There are tensions between workers who guide their expertise and practices on different sources of knowledge. As welfare agencies operate within restricted and reduced budgets, experiential experts have become cheap competitors to social workers (Van Der Heijden et al., 2011). In some care organisations, experiential experts have replaced social workers to take care of frontline contact with service-users, and the role of social work has been adapted to train and supervise experiential experts. Similarly, community-based mentors are increasingly being employed in place of youth workers, with ongoing tension between the two types of worker (Baillergeau & Hoijtink, 2010; De Tolk & Hazekamp, 2014). Furthermore, limited job opportunities and unfavourable labour market conditions mean that peer workers’ legitimate expectations of moving from part-time to full-time work may not be met (De Jong, 2013).

There is ambivalence amongst professionals towards experiential experts as their increased role may be part of a de-professionalisation agenda (Duyvendak, Knijn, & Kremer, 2006). However, such concerns do not undermine the validity and recognition of experiential knowledge as an important resource; rather it relates to the embodiment of such knowledge by a specific actor in a specific context who also claims clinical knowledge. We develop our analysis of the grounds of the recognition of experiential knowledge further by returning to our schema for appreciating the characteristics of ‘knowing otherwise’ as a resource for action.

**Different modes of recognition of experiential knowledge**

In this section we consider the resources that experiential experts claim to use when reaching out to and mentor youth at risk. We furthermore compare their views with those of service commissioners and practitioners and service-users.

In our studies (Baillergeau et al., 2014; 2009) we identified a number of criteria that individuals had to fulfil if they wanted to act and be employed as experiential experts. These criteria included having experience of a relevant condition, having developed their own coping strategies and having ‘recovered’. Experiential experts claimed to use these elements frequently in their practice. For example, they claimed that having knowledge of how it feels to have problems at school and to experience frequent truancy enables them to build a trust relationship with the young people who dropped out of school. Furthermore, being aware of the rewards of crime and possessing intimate knowledge of the local area enabled them to have informed discussions with at-risk young people. They described the ways they had learnt to perform as rolmodellen through a process of ‘trial and error’ and an awareness that they possessed ‘hidden talents’ and the motivation to explore them. Experiential experts noted the benefits of their visible success, for example through owning a music school or a kick-boxing gym, were demonstrated to at-risk young people that they could make it and such success could provide these young people with hope.

While these were essential criteria, experiential experts identified other resources that were helpful for building trust with marginalised young people. These included experiences of multiple connected difficulties, for example debt plus stealing, and the social consequences of a condition such as discrimination or stigma linked to race or religion. This additional group of used resources was not explicitly framed as a requirement for the job or advocated by commissioners, although they were not outright dismissed.

We also identified a third group of resources used by experiential experts that were subject to debate or even contestation among other stakeholders, such as the experience of institutions or of alternative insights. For example, the experience of educational
institutions and having had a negative experience of formal schooling was repeatedly voiced as an asset to really grasp what young people experience and why they feel hopeless and desperate about their chances in mainstream society. Likewise, the experience of alternative resources such as meeting a ‘self-made’ role model was a turning point in the lives of a few experiential experts. Some even used the profile of self-made role models to argue in favour of experiential experts-led youth work (De Tolk & Hazekamp, 2014).

These two latter sets of experiential resources are commonly subject to debate, however, especially when related to negative experiences of institutional responses. That said, we did not find the debate to be a contestation of the negative experiences of institutional responses per se; rather, the debate confronted the rejection of the institutional responses as a whole and the intention to replace these with approaches fully informed by experiential knowledge. Such an alternative anti-institutional approach, in its disregard of academic knowledge, raises serious questions and potential problems. In such an approach, the possibilities for dealing with uncertainty by building upon a wider range of knowledge would be missed. Hence, uncertainty would not be resolved but rather relocated.

**Conclusion – beyond ‘wrong knowledge’**

There is evidence in the Netherlands that experiential experts are recognised and making a substantial contribution in some health and welfare services. Such experiential expertise is derived amid challenging lives that are difficult for outsiders to grasp. Such expertise provides a way of understanding the difficult circumstances faced by at-risk individuals and enables them to identify practical resources for coping strategies or problem solving amid uncertainty. Experiential expertise is therefore an important resource for long-term recovery and for enhanced social inclusion/participation and user empowerment. As such, experiential knowledge builds upon social processes and interactions involving individuals, in which structural and inherent components – as framed by Walklate (2011) – are threads of a larger fabric that is constantly changing as a result of interactions. When turned into practice, experiential knowledge can offer a variety of resources to help tackle social problems more effectively. While observing and analysing peer work and experiential expertise, we identified eight ways in which people at risk ‘know otherwise’, to see problems in a different way to normal professional perspectives. Such difference involves understanding how behaviours that appear irrational, immoral or antisocial are ‘reasonable’ in certain contexts, how individuals at risk (negatively) experience their interactions with organisations that are supposed to help them and how they have learnt (often dysfunctionally) to cope with difficult circumstances. Being able to ‘know otherwise’ does not mean that experiential experts will necessarily use this knowledge effectively and beneficially or that such insights will be acknowledged by other stakeholders. While such knowledge may not help individuals address their immediate problems, the ‘knowing otherwise’ of experiential knowledge may be of a greater value for longer-term trajectories and wider understandings of recovery in the face of risks (Anthony, 1993; Renn et al., 2011).

In the Netherlands, the development of lived experience as a resource for intervention to some extent reflected criticism of the hegemonic power of ‘expert knowledge’ regarding situations characterised by high uncertainty. In these contexts, it seemed necessary to make use of the experience of usually silent stakeholders: people deemed at-risk. ‘Experiential expertise’ developed as a ‘better alternative’, often – at first – outside of care institutions. Meanwhile, extended forms of multifaceted responses have developed.
through which lived experiences of ‘experiential experts’ are assumed to complement decontextualised scientific knowledge. As a result, holders of experiential knowledge have been engaging in care provision, alongside professionals grounded in scientific and clinical knowledge or, in certain circumstances, as the central actors. When working in partnership, experiential experts have become part of multifaceted responses to situations imbued with uncertainty, drawing on various forms of ‘deep knowledge’ of situations, experiential knowledge included. When taking a lead role, then experiential experts have become the main response provider, building on their experiential knowledge but also on a degree of professional expertise stemming from non-experiential sources of knowledge, thereby developing a bricolage approach (Horlick-Jones et al., 2007) while working fairly independently.

The rise of experiential experts reflects a certain recognition of experiential knowledge as an additional resource for responding to issues of uncertainty. There is scope for further research in this area to explore whether this recognition of experiential knowledge as a worthwhile component of responses to situations of uncertainty necessarily entails discarding clinical knowledge of frontline professionals such as nurses, medical doctors, social workers, probation officers and teachers. Where this is deemed less appropriate, it is important to consider how experiential knowledge can be used most effectively in combination with expert knowledge.

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Note

1. Nevertheless, it should be noted that not all experiential experts operating with youth at-risk are satisfied with relying only on their own experiential knowledge. Some regard as problematic the fact that ‘regular’ social professionals do not (or cannot) actively support them through coaching or inter-vision (Baillergeau et al., 2009).

References


De Jong, J. D. (2013). Rolmodellen en het risico op recidive. Een mentor als positief rolmodel ter vermindering van criminaliteit van jonge Amsterdamsse veelplegers [Role models and the risk of re-offending. A mentor as positive role model in favour of criminality reduction among young repeating offenders in Amsterdam]. Amsterdam: Rebond/Gemeente Amsterdam.


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