

Background: Health in Roma Communities

My research focuses on people who self-identify as members of the Roma ethnic group. Studies of Roma health conducted across Europe have identified lower life expectancy and lower self-reported health status [1]. These problems are attributed to a range of factors, including poorer access to health services and discriminatory behaviour of service providers [1].

With regard to health communication, community members are reluctant to discuss sexual and reproductive health, and consider the associated body parts 'unclean' [2]. Mental health is also a particularly stigmatised subject, and acknowledging mental health problems can be damaging not only to an individual's reputation, but also to an entire family's standing in the community [3].

Amongst Roma community members with long-term and complex conditions – many of whom live on low income – Personal Independence Payment (PIP) provides a vital source of support.

Methods

Participant Observation

During four months of health advocacy volunteer work with the Roma Support Group (RSG), I conducted 30 PIP-related health advocacy meetings with Polish Roma service users. I helped to complete:

- 20 PIP forms
- 2 mandatory reconsiderations
- 3 appeals
- 5 calls to DWP to request forms

Interview Data

My participant observation provided a set of topics to explore in semi-structured interviews with Roma community members. After five interviews with community members in different stages of the claim process, as well as one with an RSG health advocate, I found that no new themes were emerging from my analysis of interview data. Having reached data saturation in London, I will move on to conduct further PIP-related interviews at my second research site in Luton.



Canning Town, East London, near the Roma Support Group Office

What is Personal Independence Payment?

- PIP is a disability benefit introduced under the Welfare Reform Act of 2012 to replace Disability Living Allowance (DLA).
- It was introduced in response to the high cost of DLA to the government and, purportedly, is intended to streamline the benefit assessment process [3].
- Claims are assessed on the basis of information provided in the PIP form and a face-to-face assessment with a health professional contracted by consulting firms Atos and Capita.

The PIP Claim Process

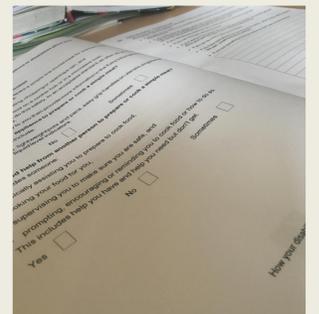


Findings: Narratives and Emergent Themes (Columns represent themes; background colours represent distinct personal narratives)

Language Barriers and Lack of Confidence in Communicating	Impacts of Health on Family Life: Fear, Uncertainty and Shame	Disrespectful and Dismissive Attitudes of Assessors	Underlying Concerns about Mental Health
<i>Language and respect:</i> "You see I'm not talking good English, my English is low, very low. The people ignored me." (Interview 1)	<i>The social/political context of health benefits:</i> "I got child disabled. What my situation, I don't know, nobody help me because I'm not working. My fear for this country." (1)	<i>At the assessment:</i> "I feel like he ignored some facts, like he didn't care that [my husband has] got some oxygen with him." (5)	"And, you know, [my husband has] got anxiety, which is probably connected to his physical problems, like depression." (5)
<i>Filling in the form:</i> "It was complicated questions to answer, basically I didn't know what to answer, how to understand." (2)	"One day I am going to be old and will need more help. I need help but I will not ask my family for help." (3)	"[The assessor] didn't explain anything, so when he finished, just sat down next to his desk and probably was just ticking some box, or you know how it goes in the computer." (5)	<i>From fieldnotes (13/04/2016):</i> "Nearly every PIP meeting begins with a discussion of physical health, yet depression and anxiety almost always come up as areas of concern."
<i>Use of telephone interpreters:</i> "It was hard to understand, and also it was difficult to express ourselves and to describe everything. You know, like when you have to talk to the phone and not to the real person." (2)	<i>Elaborating on cultural context:</i> "I have to find the balance between the question and my answering. Same with answering questions about the bath and shower. [The assessors] will ask why I don't ask for help" (3)	<i>Communication with the assessors:</i> "If some people understand you clearly and they will try to put themselves in your place, then it would be good, but some of the people, they are just rude." (4)	<i>Personal health history and its impacts on daily life:</i> "I would like to . . . feel more comfortable with my mental health so I can cooperate with the other people, so I can help my children out." (4)

"The questions are hard – not the questions but the answers. I need the help, but because of my culture I cannot say." (3)

- Roma Support Group Service User



A page of the PIP form

Discussion: Critical Reflections on PIP

Participants in all stages of the claim process report substantial difficulties in describing their disabilities and communicating with assessors. Underlying the barrier created by limited English language skills, many community members have additional difficulties with answering the questions even when translated directly into Polish. As they are phrased in the claim form, the assessment questions, focusing on ability versus inability to complete a specified set of tasks, do not match community members' conceptions of health and preferred modes of health communication. I observe discussions of health in Roma communities to closely resemble storytelling – with origins of a condition, its development over time and its impact on relationships with others taking precedence over diagnosis, symptoms and support needs. This holistic mode of health communication clashes with the discrete assessment questions, creating a situation in which community members' descriptions of health problems do not align with the assessment criteria set by DWP.

Conclusions

For the Roma community, the process of claiming PIP brings not the only the frustration of unsuccessful attempts to communicate, but also a strong sense of fear and uncertainty. This finding is in keeping with literature critiquing the PIP system's emphasis on a 'deficit model of disability', which focuses on inability to perform certain tasks and affords claimants a narrow set of criteria for expressing the impacts of their conditions [3], [4]. Yet in addition to reinforcing these findings, this study explores the impact of different cultural conceptions of health on interactions between claimants and assessors, and offers insight into the deeper social impacts of barriers to claiming PIP. Without sensitivity to cultural differences in health communication, assessors are ill-equipped to accurately represent claimants health situations, placing vulnerable individuals in danger of exclusion from social support systems.

Next Steps

Investigate observed differences in demand for assistance with PIP at London and Luton research sites, looking at reasons why some segments of the Roma community are much more hesitant to claim PIP than others.

Contextualise PIP within the wider benefits and social services environment, addressing how the PIP claim process compares with other benefits and how it comparatively impacts on community members' perceived quality of life.

References

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