BECOMING AN EXPERT: IDENTITY CONSTRUCTION IN NARRATIVES OF PEOPLE WITH MENTAL DISORDERS AS DISCLOSED IN MEDICAL CONSULTATIONS AND ON YOUTUBE CHANNELS

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BACKGROUND: PATIENT EXPERTISE

• With the advent of new technologies and health information easily accessible, new forms of patient participation in healthcare appeared. Many healthcare systems and institutions prioritize and promote the active involvement of patients in self-management of their chronic conditions (Prestin and Chow 2014; Locher and Thurnherr 2017; Bellander and Landqvist 2018; Newman et al. 2004).

• A growing number of patients adopt an active approach to their own treatment (Fox et al. 2005; Haldal and Tjora 2009). The patient becomes, to different extents, a medical expert who may challenge the traditional positioning of the doctor (Ziebland 2004).
BACKGROUND: IDENTITY

• Identity is a dynamic and negotiable process that takes place in specific interactional occasions, and this process is embedded in social practices within which discourse practices play a central role (Bucholtz and Hall 2005). Identities, as well as expertise, are thus socially and discursively constructed.
OBJECTIVE

• To explore how patients with depression discursively construct their identity and expertise – an aspect of identity. In particular: patient expertise is manifested through adopting an active role towards illness and exercising some sort of control over symptoms and treatment.

• The participants present themselves as sources of experiential knowledge - they share knowledge based on their lived experiences and third party interactions (with specialists or peers).
DATA

• 3 case studies of patients with depression, coming from three different contexts: semi-structured interviews with Polish patients with medically unexplained symptoms and mental disorders (collected as part of the NCN project: 2013/11/B/HS2/02449), medical consultations with Chilean university students (Fondecyt project 11191027) and Polish YouTube personal accounts of living with a mental illness.
CASE STUDY 1

• A student patient, 28 years old, female, Chilean

• Major symptoms reported in the interview: panic attacks, memory lapses, blackouts, self-harm

• Diagnosis: depression with suicidal ideation
Doctora: Ya, ahora volvamos a este año. Ahora ya sientes que te vas a empezar a sentir igual, ¿eso?

Paciente: Sí, el tema es que de un tiempo a esta parte ya presiento cuando me va a dar, como que ya sé mi límite de estrés o de preocupaciones que ya siento o digo: o me relajo o me va a volver a dar. El tema es que muchas veces la rutina a uno no permite relajarte o hacerte al lado y despejarte.

Doctora: Difícil, y más en la universidad.
EXTRACT 1: TRANSLATION

• **GP:** Ok, now let's go back to this year. Now do you already feel that you are going to start feeling the same, yes?

• **P:** Yes, the thing is that for a while now I can feel when it is going to happen, as I already know my limit of stress or anxiety that I feel or say: I either relax or it will happen again. The thing is that most of the time the routine does not allow you to relax or step aside and clear up.

• **GP:** Difficult, and even more at the university.
• The patient presents herself as a source of experiential knowledge

• Her expertise is constructed based on her lived experience - she can determine the moment when her symptoms appear, she knows her limits and she is aware of the circumstances which may impair her control over the symptoms
EXTRACT 2: MASKING SYMPTOMS

• D: Puede ser por ejemplo, vienen y qué te preguntan cómo estás y te da pena?

• P: Sí, sí, sí, como que siento que tengo que siempre mostrar una imagen que no es. Estoy tan acostumbrada a tener que actuar en mi casa para que mi mamá no se preocupe, que siento que lo hago en muchos lados...

• GP: It could be, for example, they come and what do they ask you: How are you and do you feel sorrow?

• P: Yes, yes, yes, I feel like I always have to present an image that is not true, AS. I am so much used to having to act in my house, so that my mom doesn't worry, I feel like I do it in many places…
• Hiding the symptoms from the family and friends is also a manifestation of some sort of control
• Self-awareness of other people and the way they will react towards her illness or the way they will perceive her (self vs. other)
EXTRACT 3: MAKING A DECISION ABOUT MEDICATION AND TREATMENT

• P: Cambié donde otro psiquiatra. Porque esa doctora me quería volver a dar las pastillas con una dosis más

• D: Ya

• P: Y yo no quería tomar pastillas. Entonces fui donde una psicóloga con que trabaja con terapia alternativa. Empecé con ella un tratamiento, pero me dijo que no podía dejar las pastillas que me había dado el psiquiatra.

• P: I changed the psychiatrist. Because that doctor again wanted to give me the pills with one more dose

• GP: Yes

• P: And I didn't want to take pills. So I went to a psychologist who works with alternative therapy. I started treatment with her, but she said I shouldn’t stop taking the pills the psychiatrist had given to me.
COMMENTS

• A clash between *expert* expertise and patient expertise
• Adopting an active role toward the treatment – taking decision about medication and treatment
• The patient presents herself in action terms (*I changed*…, *I went*…, *I started*…) (cf. Galasiński 2008)
CASE STUDY 2

• A student patient, 27 years old, female, Polish; she has been presenting symptoms for 15 years

• Major symptoms reported in the interview: blackouts, panic attacks, suicidal thoughts
• Lekarz: A słuchaj, czy jakieś leki teraz bierzesz z tego powodu?
• Pacjent: Jak się bardzo zdenerwuję to biorę hydroksyzynę. Ale żadnych leków, już w swoim życiu wzięłam tyle, że staram się nie brać. Z wiekiem staram się bardziej panować, bo jestem bardziej świadoma swojego problemu niż kiedyś, bo kiedyś, jak się to zaczęło, to nie wiedziałam jak reagować, co zrobić. Teraz mimo że objawy są inne to staram się nad nimi panować, często nie wychodzi, ale jestem bardziej tego świadoma.
GP: And ... Listen, are you taking medication now because of this?

P: If I get very angry, I take hydroxyzine. But no medication, I've already taken so much in my life that I try not to take it. As I get older, I try to have more control because I'm more aware of my problem than I used to be, because once, when it started, I didn't know how to react, what to do. Now, despite the fact that the symptoms are different, I try to control them, it doesn’t usually work out, but I am more aware of that.
• Adopting an active role toward treatment – making decisions about medication

• Patient expertise developed over time - learning about the symptoms and how to control them to some extent, becoming self-aware
EXTRACT 2: ATTITUDE TOWARDS HEALTHCARE

• L: …czy masz jakieś specjalne oczekiwania, wiesz, od opieki zdrowotnej…

• P: No to znaczy, ja bardzo chciałabym, żeby… był znaczne większy dostęp do psychologów, bezpłatnych psychologów. Bo problem leży w tym, że kiedy u mnie się zaczęły te problemy, to był… była jedna placówka na Mickiewicza i żeby dostać się gdzie indziej, było to niemożliwe, a jeśli już było możliwe, nie wiem, nie dotarłam do takiego miejsca, a ośrodki, które są teraz… są tragiczne, bo bezpłatne, terapie, tak jak ja uczęszczałam wiele lat, to była porażka. Gdyby nie farmakologia, to ja nie miałabym żadnego wsparcia. (...) I tak naprawdę, skupiamy się na, ja to tak odczuwam, na leczeniu fizycznym, gdzie moim zdaniem leczenie psychiczne nie to że jest to ważniejsze, ale jest równie ważne i od tego zaczynają się również problemy fizyczne, a nie ma dostępu.
• **GP:** ... do you have any special expectations, you know, from healthcare ...

• **P:** Well, I mean, I really wish there were much greater access to psychologists, free psychologists. Because… the thing is that when my problems started, it was... there was one outpost at Mickiewicza Street and getting elsewhere was impossible, and if it was possible, I don't know, I didn't find such a place, and centers that are now ... are tragic, because they are for free, therapies I took part in many years ago were a failure. If it hadn't been for pharmacology, I wouldn't have any support. (...)

• And what we really focus on - I feel it that way - is physical treatment, where, in my opinion, mental treatment - not that it is more important - is equally important, and this is also where physical problems start, and there is no access [to psychological help, AS].
• Patient expertise is constructed through patient’s experiential knowledge: negative personal experience with past therapies and an explicit critique of Polish healthcare and limited access to good quality and free psychological help
EXTRACT 3: THE PAST VS. THE PRESENT, MASKING SYMPTOMS

• P: Nie, one są inne, bo wtedy było bardzo dużo objawów fizycznych, a teraz jako że człowiek musi pewne rzeczy maskować, to nie pozwalam sobie na fizyczne objawy, w takim sensie, żeby było to widać, tylko bardziej to wszystko się przenosi do głowy (...) więc na pewno one są inne i na pewno za 5 lat też będą inne. Ja tak to postrzeganam: kiedyś to było tak , że ja bardzo pokazywałam, że się denerwuję, że ja sobie nie poradzę i wszyscy w otoczeniu o tym wiedzieli, tak teraz jeśli cokolwiek się dzieje, to wszystko zamykam w sobie, żeby właśnie ludzie nie myśleli ze jestem słaba, to i wszystko toczy się w głowie później. (…)

• L: (...) bardzo ci dziękuje. Dzięki, że tyle rzeczy dowiedziałem się i nauczyłem się, po to to robię, natomiast będzie służyło to żeby zmieniać też lekarzy i zmieniać system (...) wiele osób sobie nie zdaje sprawy że takie są oczekiwania

• P: Po to tu przyszłam. Dlatego, że choroba fizyczna jeśli jest widoczna, to zazwyczaj się widzi, widzą ludzie, jeśli ma się raka, to nie ma się włosów, bo jest się po chemioterapii, a jeśli ma się problemy psychiczne, to tego nie widać, więc, tu jest problem.
The GP is asking whether the symptoms are the same or different...

- **P:** No, they are different, because there used to be a lot of physical symptoms, and now that you have to mask certain things, I don't allow myself to have physical symptoms so that they can be seen, so everything moves to the head. (...) So for sure they are different, and they will be different in 5 years. (...) I perceive it this way: I used to reveal my symptoms when I was nervous, that I could not cope and everyone saw it, so now if anything is happening, I am closing everything so that people don't think I am weak, and everything goes on in my head later.

- **GP:** (...) thank you very much. Thanks, I've found out and learnt so much, that's why I'm doing this, it will help to change doctors and change the system (...), many people do not realize that such are the expectations...

- **P:** That's why I came here. If you have a physical illness, you usually see it, people see it, if you have cancer, you don't have hair, because you have chemotherapy, and if you have mental problems, you can't see them, so here's the problem.
• Expertise: the patient claims to have control over her physical symptoms (*I don’t allow myself to have physical symptoms, I’m closing everything*) and is aware of the symptom trajectory (*they will be different in 5 years*); she adopts an active role towards her illness, presenting herself in action terms

• A kind of contradiction: the patient admits to masking the symptoms, on the one hand (so that people don’t perceive her as weak; self vs. other), but on the other hand finds it problematic that they are not shown

• Sharing personal experience with the audience in order to raise awareness, have an impact (educational element)

• Swapping the roles: the GP admits to learning from the patient
CASE STUDY 3

• The female vlogger (24 yrs old) running her YouTube channel since 2014 under the pseudonym, suffering from depression. No biodata in the About section of the channel but she is present on other social media where she is not anonymous.

• Real life identity revealed also through the promotion of her book she published recently (Eng. How not to kill yourself and not to go mad)

• Interest in photography

• Her first YouTube videos were about Polish cities but now she vloggs about such topics as depression, suicide or self-destruction.
EXTRACT 1 (THE OPENING): THE PAST VS. THE PRESENT

• Zrobiłam ostatnio duży porządek na kanale i wyrzuciłam wszystkie takie filmy, które nagrywałam kiedyś. Bo stwierdziłam, że tak jakby to, co kiedyś mówiłam też było prawdą, ale miałam jakby wtedy mniej doświadczenia, mniej tak jakby wiedzy i wszystkiego (…)

• I have recently cleaned up my YouTube channel and deleted all the videos that I recorded in the past. Because I came to the conclusion that as if what I once said was also true, but I had sort of less experience, less sort of knowledge and everything (…)


The vlogger continuously updates her knowledge – based on her changing experience with living with her illness

Comparison of the past situation with the present, when the vlogger has acquired more experience and knowledge

Evidence of situated expertise (Mackiewicz 2010), i.e. expertise that is built over the vlogging channel but also through the vlogger’s multiple presence on other social platforms (they often have their own websites or they are present on other social media, such as Instagram, Facebook or Snapchat); in case of this vlogger, also publishing a book on young people’s mental problems
EXTRACT 2: DIFFERENT KINDS OF SUICIDE

• Jest kilka rodzajów samobójstwa - w sensie chciałabym to zostawić na inny odcinek – ale jest coś takiego jak samobójstwo pod wpływem impulsu czy samobójstwo zaplanowane. No, są różne rodzaje.

• There are several types of suicide - I would like to leave it for another video - but there is such a thing as impulse suicide or planned suicide. Well, there are different types.
• Expertise through knowledge sharing, no explicit references to medical sources though, just emphasis of the vlogger’s own experience

• Confirmation of the educational function of the video (Lange 2014)

• Announcement of the intention to continue with the topic, some form of self-promotion of her channel; confirmation that she has the "ordered" knowledge to talk about the topic
I jak wyleczyć depresję? Pewnie każdy wam powie, że warto wziąć tabletki, warto sie leczyć tabletkami. Mnie nawet moja prababka proponowała, żebym ja wzięła tabletki. Tabletki na przykład na początku terapii bardzo mogą pomóc, bo ktoś może być tak bardzo już zniszczony od środka, i może nie widzieć nawet sensu pójścia na terapię, że te tabletki mogą na początku pomóc mu mieć chociaż odrobinę lepszego samopoczucia, żeby on był w stanie iść na tą terapię. Ale….. w niektórych przypadkach po prostu tabletki nie działają. Ja brałam tabletki na depresję, różne, naprawdę, wypróbowaliśmy strasznie dużo różnych tabletek na depresję. Tyle, że zawsze coś było nie tak. Albo miałam fizyczne objawy, w sensie, że na przykład rano budziłam się i cała się trzęsłam. I dla mnie to było strasznie… tak jakby męczące. I ja czułam się ciągle jakbym byłem naćpana, i strasznie tego nie chciałam. W innym przypadku było mi niedobrze, albo bolała mnie głowa, albo miałam zawroty głowy, albo mdlałam. I zawsze coś było nie tak (…)

EXTRACT 3: HOW TO TREAT DEPRESSION
And how to treat depression? Probably everyone will tell you that it is worth taking pills, it is worth being treated with pills. Even my great-grandmother suggested that I should take pills. Pills, for example, at the beginning of therapy can help a lot, because someone may be so badly damaged inside and may not even see the point in going to therapy that the pills may initially help him to be at least in a better mood so that he would be able to start the therapy. But ... in some cases pills simply do not work. I took pills for depression, different, really, we tried a lot of different pills for depression. It's that there was always something wrong. Or, I had physical symptoms, in the sense that, for example, I woke up in the morning and I was shaking. And for me it was terribly ... as if tiring. And I always felt as if I was stoned, and I didn't want to. In a different case, I was sick, or my head hurt, or I felt dizzy or fainted. And there was always something going wrong ...
COMMENTS

• Construction of expertise and identity related to the medium. The vlogger explores the technological affordances of YouTube to construct an authentic and engaging identity

• Elements of interdiscursivity: the vlogger's narration includes elements of instruction and advice. The vlogger adopts a popular HOW-TO vlogging style (Bhatia 2018; Burgess and Green 2018)

• By the end of the extract, the vlogger refers to her own personal experience with the pills. She refers to herself as an expert, her self-reflective account of her own experience authenticates the advice she gives
Ja wiem, jak to jest mieć depresję. Ja wiem jak to jest strasznie ciężko. Ja was bardzo rozumiem i wiem, że może być wam strasznie ciężko się leczyć ale trzymam za was bardzo kciuki, że będziecie chcieli się leczyć, że będziecie chcieli żyć. Bo życie jest naprawdę piękne, tylko przez niektóre momenty albo wydarzenia w naszym życiu tego nie widzimy. Ale możecie mi uwierzyć, że naprawdę takie jest (...) Mam nadzieję, że poczujecie się lepiej, że zaczniecie się leczyć. I że będzie dobrze.
I know what it's like to have depression. I know how hard it is. I understand you very well and I know that it may be very difficult for you to undergo treatment but I keep my fingers crossed for you that you will want to have treatment, that you will want to stay alive. Because life is really beautiful, only because of some moments or events in our lives we do not see it. But you can believe me that it really is (...) I hope you will feel better, and that you will start to have treatment. And that everything will be fine.
A change of perspective: emphasis put on personal experience is used to validate the vlogger’s empathy and understanding of the audience.

Building a close, intimate relation with the audience through inclusive language and words of comfort.
SUMMARY

• In both YouTube and medical consultations – patient expertise manifests itself in the ability to control symptoms to a certain degree and in the participants’ self-reflection about the trajectory of their illness (the past vs. the present). Patients authenticate their expertise by drawing on their lived experience of living with depression.

• Patients in medical consultations also reflect about the way others perceive them. They admit to hiding the symptoms for fear of being perceived as weak or in order not to worry the family (cf. Sowińska 2018).

• On YouTube patient identity and expertise are constructed through more direct references to the audience, advice, and recommendations

• There is also a stronger need to authenticate the expertise – expertise is linked to credibility and trustworthiness on YouTube channel (visible in the comments under the video)
CONCLUDING REMARKS

• The participants adopt an active role in making sense of their illness
• Their expertise is constructed through their lived, unique experience and involvement
• Their self-reflective accounts of living with an illness have a therapeutic and educational value
• Their accounts promote the sense of control and empowerment
• Yet, patient expertise contests medical expertise and leads to patient non-compliance (giving up medication)
REFERENCES


