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A 'near-life experience': lived experiences of spirituality from the perspective of people who have been subject to inpatient psychiatric care

Tiburtius Koslander RN, PhD (Quality of Nursing Care Manager)¹, **Sonia Rönning** RN, MSc (Psychiatric Nurse)^{2,3}, **Sofia Magnusson** RN, MSc (Psychiatric Nurse)^{2,3} and **Lena Wiklund Gustin** RN, PhD (Associate Professor, Professor)^{2,4}

¹Integrierte Psychiatrie Winterthur – Zürcher Unterland, Winterthur, Switzerland, ²School of Health, Care and Social Welfare, Mälardalen University, Västerås, Sweden, ³Division of Psychiatry, County Council of Dalarna, Falun, Sweden and ⁴Department of Health and Care Sciences, UiT/The Arctic University of Norway, Tromsø, Norway

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Aims: To describe lived experiences of spirituality from the perspective of people who have been subject to inpatient psychiatric care and to interpret these experiences from an understanding of health as dialectical.

Methods: After approval from a regional ethical board, eleven participants were recruited from two organisations for people with mental health problems. Participants were asked to narrate about spiritual experiences and occasions where such experiences had come close. The transcribed interviews were analysed by means of a phenomenological hermeneutical approach.

Findings: A structural analysis of the text resulted in three themes; perceiving the presence of something extra mundane, making sense of reality and struggling for acceptance. The comprehensive understanding highlights spiritual experiences as going beyond religion, even though religious experiences appear as part of it. These experiences can indeed be a resource contributing to

experiences of hope, connectedness, meaning and coherence in life. However, they can also give rise to doubt, anxiety and feelings of loneliness and hopelessness. Rather than understanding spiritual experiences as being either 'good' or 'bad', we could approach spirituality as something that is always present in alternate and interrelated forms. Metaphorically, this could be understood as a 'near-life experience', summarising participants' experiences related to their struggle with issues related to suffering and health which are simultaneously present. Conclusions: If psychiatric nurses could approach this complexity and, without being judgemental, explore seemingly positive and negative experiences of spirituality as dialectically related to each other, rather than viewing them as either resources or problems, this could contribute to insiderness care and hopefully also support people who struggle with these experiences to seek help when needed.

Keywords: existential experiences, mental health, patient perspective, phenomenological hermeneutics, psychiatry, spirituality.

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Introduction

According to Greasley et al. (1), mental health issues and spirituality are closely related, and people struggling with mental health issues might often encounter intense spiritual experiences. Historically, such experiences have often been understood as signs of mental illness (2). However, spirituality has also been described as a

resource and part of being human (3,4). This is in line with a shift towards holistic, person-centred and recovery-oriented approaches in recent decades.

There are numerous definitions of 'spirituality'. These definitions often include searching for the meaning of life or striving to fulfil what people cherish as their purpose in life, as well as having a sense of connectedness to universe and humanity. Many definitions also involve a faith in a God or a higher power, but a person might also have spiritual experiences without being religious (5,6). Sometimes, these nonreligious spiritual experiences have been called existential, and focus has been on people searching for meaning and struggling with issues related

Correspondence to:

Lena Wiklund Gustin, School of Health, Care and Social Welfare, Mälardalen University, Box 883, S-721 21 Västerås, Sweden. E-mail: lena.wiklund@mdh.se to life and death (7,8). Even though we acknowledge that it might be valuable to have a discrepancy between the spiritual and the existential in theory construction, we have used the concept 'spiritual experiences' in a wide sense that may or may not include religious experiences and/or existential thoughts. This use of the concept is further motivated as the study is concerned with people's experiences of spirituality, rather than their experiences in relation to a strict definition of spirituality. Furthermore, in line with person-centred and recovery-oriented traditions in psychiatric care, recovery is understood as a process, rather than a state (9,10).

Background

As described by Wilding et al. (11), mental ill health can increase people's awareness of their spirituality. When people strive to understand why they have been afflicted by mental health problems and struggle with questions about the meaning of their lives, answers can be sought in religious and spiritual practices (12). This can contribute to experiences of meaning and coherence in life, as well as a sense of being in community with others (13,14). Having a faith and trusting some kind of God or higher power can install hope for the future. This can help a person to cope with challenges associated with mental health problems (11,15).

However, spiritual experiences can also be frightening and cause suffering. Experiences of being persecuted, influenced and/or abandoned, as well as feelings of alienation, loneliness, hopelessness, doubt and anxiety, can be painful (16,17). Furthermore, doubt about the authenticity of the experiences as well as difficulties interpreting the meaning of them might also be troublesome for the person (18,19). If persons believe that their suffering is a spiritual rather than a medical problem, and/or that what happens is predetermined and that they must rely on the will of a higher power in order to recover, they can be passive and unwilling to seek help from healthcare professionals (12,14). In addition, a fear that professionals will either ignore these issues or perceive them as signs of the person being odd, or mentally ill, can also obstruct help seeking (5,20).

Hence, addressing spiritual needs is described as a core issue for supporting recovery (21-23). However, if professionals lack understanding and reflective skills, then this can be challenging (24). When faced with 'spiritual-type' experiences, nurses focus on the outcome rather than the nature of the experiences. This forms the basis for their assessment of the patient's caring needs. Experiences considered as having a positive outcome for the patient tend to be understood as spiritual, while those with a negative impact are assessed as psychotic symptoms (25). Furthermore, professionals also struggle to differentiate between religious beliefs related to the

patient's background and psychotic experiences and beliefs. Nurses tend to focus on the latter when communicating with patients (26,27). These would be thought of as 'ordinary' experiences, and general practices and beliefs close to the ones of undiagnosed people, usually considered as resources. These are also related to spiritual needs and in focus for nursing interventions (28-30). Experiences that go beyond the ordinary tend to be described in terms of religious delusions or hallucinations (31,32). In addition, spiritual practices from other cultures might be experienced as challenging and hard to accept as resources (33).

Focus and aim

If experiences that patients understand as spiritual are understood as symptoms by professionals, it might be hard to address spiritual needs in an adequate way as this can undermine an understanding of recovery-oriented care as a journey, rather than a destination (10,30). Rather than just striving to support clinical insight, that is understanding one's experiences from a biomedical perspective, caregivers are encouraged to support patients' searches for narrative insight (34). The latter has been described as 'a meaning-making in which the awareness of experiences is contextualised within the individual's world view and therefore provides a more robust foundation to move forward' (34, p. 76). Furthermore, in line with a caring science perspective, and a recovery-oriented approach to psychiatric care, health is not understood as being in a dichotomous relationship to illness. Rather, it is conceptualised as a dialectic process, comprising both health and suffering (35,36). Hence, the aim of this study was to describe lived experiences of spirituality from the perspective of people who have been subject to inpatient psychiatric care and to interpret these experiences from an understanding of health as dialectical.

Methods

The project was initiated by the first author who introduced the idea to the head directors of two organisations for people with mental health problems and to the last author. After approval from a regional ethical board, the first author introduced the project to people who participated in day care activities run by the two organisations. Information about the aim of the study, about the audio recorded interviews, about confidentiality and outlining the possibility to withdraw without giving any reason were given both in writing and orally. Five women and six men volunteered. The participants' age varied between 18 and 65, and all had had one or more episodes when they had been subject to inpatient psychiatric care. Participants were interviewed by the first

author and asked to narrate about spiritual experiences and occasions where such experiences had come close, how they experienced these occasions and how it affected their mental health. Follow-up questions were posed in order to support narration (37).

The interviews were transcribed verbatim and analysed means of a phenomenological hermeneutical approach inspired by Lindseth and Norberg's (38) application of Ricoeur's theory of interpretation. In line with Ricoeur's (39,40) thoughts about understanding as evolving from the dialectic relationship between understanding and explanation, the method has three interpretive steps. The first step, the naïve understanding, is based on the repeated listening and readings of the transcribed interviews and aims at a preliminary interpretation of the meaning of the text on an overall level. In the following step, focus shifts from the whole towards the parts and from understanding to explanation. As described by Ricoeur (40), these explanations are not a matter of explaining the experiences as consequences of specific causes. Rather, they explain the meaning of the text by focusing on structures in the text. This decontextualisation and focus on the text as parts is also a means of creating a distance to the text and of challenging and/or validating the preliminary, naïve understanding. Following Lindseth and Norberg (38), we adopted a thematic analysis of the structure. The text was divided into meaning units where utterances that reflected the study aims were identified and condensed. The condensed meaning units were compared and reflected on, and a structure with themes and subthemes evolved. In the last step, the comprehensive interpretation and the previous interpretations were reflected on in relation to literature and thus recontextualised into a wider context in order to create a new understanding of the whole.

Findings

In this article, we have followed a common way to present this final interpretation. Like researchers in different contexts (41-43), we present the naïve interpretation and the thematic structural analysis in this section and integrate the comprehensive understanding with the discussion of findings. In the presentation, we use the concept 'person' when describing participants' spiritual experiences in general. The concept 'patient' is used when focus is on experiences from clinical settings and related to the role the person has in such contexts.

Naive understanding

In the same way as other people, persons suffering from mental health problems have experiences they describe as spiritual and existential. On an overall level, these experiences are not only religious, and they are also understood as personal, unique experiences which are experienced as hard to share with other people. During periods when the person's mental health problems increase, such experiences can be more intense and be a source of comfort and strength as well as fear. Patients experience a need to talk about these issues, but are simultaneously afraid of doing it, as mental health professionals are perceived as uninterested or interpret these experiences as illness symptoms. Not being able to talk freely about these issues might leave patients with a feeling of loneliness and even hopelessness, but it is also comforting to have this connection with an external force such as God.

Structural analysis

The structural analysis resulted in three themes and thirteen subthemes, summarised in Table 1. In the following text, the themes are presented as subheadings, while subthemes are written in italics. In order to come close to participants' lived experiences, themes and subthemes are described in the present tense. P and a number in brackets (P1-P12) are used to associate quotes to participants.

Perceiving the presence of something extramundane. Spiritual and existential experiences are described as an awareness of something that is outside oneself, something 'great and unspeakable' (P7) that 'observes everything' (P8). Even though this presence is neither visible nor heard, it is yet perceived as something notable, something that is always present for good and for worse, and to people experiencing life as predetermined.

But I do think about it now and then, that I can't change my life, as somebody has already paved the

Table 1 Overview of findings

Themes	Subthemes
Perceiving the presence of something extra mundane	Experiencing life as predetermined
	Receiving guidance
	Being afflicted by a dark force
	Connecting to humanity
Making sense of reality	Providing meaning and orientation
	Questioning the will of God
	Finding solace in one's experiences
	Receiving strength and support
Struggling for acceptance	Being fearful about talking about
	spiritual and existential experiences
	Not being taken seriously
	Not belonging anywhere
	Managing on my own
	Becoming appreciated by others

way. All I can do is to accept it and make the best of what life brings about. (P4)

By accepting the will of a higher power, it is easier to accept that life does not turn out to be as one dreamt, and that one's own plans fail. Hence, hard periods in life might be easier to cope with. This presence is also a source of *receiving guidance*.

I used to pray to him, for help (...) And I feel that somebody is by my side, protecting and guiding me. (P1)

This guidance is experienced as more 'honest' than advice from fellow human beings and supports experiences of security and wellbeing. Hence, praying becomes a way of finding answers to questions the person struggles with and of dealing with difficulties encountered in life. However, this presence can also be perceived as scary, a dark threat and even as if the devil himself was present. This can be experienced as *being afflicted by a dark force*, leading to actions that one regrets afterwards, or seeing and hearing things.

And then, it was this spiritual about the devil or something like that. And then something terrible happened with me at home. Suddenly everything becomes darker for me, everything becomes darker and darker. (P6)

Experiences related to the extramundane are not always described as related to good or evil forces. The subtheme *connecting to humanity* is also part of experiencing the presence of something that encompasses more than one's own life, for example becoming more understanding, and less judgmental as one 'becomes humble for what it means to be human' (P3). This does not mean that spiritual and existential experiences are understood as being alike, rather they are described as a part of being human in one's own unique way, something 'sheltered inside, something personal that you always carry with you (like others do in their own way)' (P2).

Making sense of reality. Spiritual and existential experiences are involved when persons are striving to make sense of reality. These experiences are providing meaning and orientation in life, and 'give me a reason to get out of bed' (P11). On the other hand, spiritual experiences can also give rise to doubt.

My anxiety is existential. When it deteriorates, I have unrealistic thoughts (...) I question what is reality? Is it what we see? Is the tram real? Am I real? I have experienced it as I have been transparent, that others can see through me and hear my thoughts. (P10)

Experiences of not being 'at home' with one's own experiences, of not having an 'I' and doubting whether or not the spiritual experiences are for real can be painful. This can end in the person *questioning the will of God.*

I have always had a faith in God and Jesus. But there is also much doubt and anger. I direct it to other people, but most of all to God for being afflicted by the things I have encountered in life as well as becoming ill and such things. Then I ask myself 'Why me? Why am I not healthy? Why can't I be like before? (P11)

When encountering such a crisis in life the ruminations become stronger and more intrusive. Thoughts about death, about 'dying today or perhaps tomorrow' (P10) and the meaning of life stir up the existence. Simultaneously, even in the darkest moment *finding solace in one's experiences* is evident.

For me it is possible also to believe that there are evil spiritual forces that affect me. It's very positive, for if that is true then I'm not ill, and then there is hope. Isn't there? (P3)

Solace is also described as being related to aesthetic experiences, for example in terms of 'making a tune, taking it further with me on my journey. Moving on' (P10). Hence, being in contact with one's spirituality is a matter of struggling for security in life. This security is related to experiences of *receiving strength and support* from a higher power. This is a profound sense of security that persons can rely on when challenged by life.

I was lying on my bed, feeling terrible. Then there was a light that lifted me out of my body, saying "you can choose if you want to live or die. If you want to live you will receive strength". So, I chose to live, and went, well...down into my body again. (P9)

Thus, experiences of being torn between doubt and faith are rather related to one's own existence than to the existence of God or a higher power. It means to be involved in a struggle with one's own understanding of life, and the premises for one's being.

Struggling for acceptance. For persons with mental health problems, spiritual and existential experiences could be associated with experiences of being an outsider struggling for acceptance, as one's own perception of reality might differ from others. Encounters with healthcare professionals might then be characterised by a sense of being fearful about talking about spiritual and existential experiences, as professionals might interpret such experiences as symptoms.

If you tell them about it when you are at the hospital, then they think... Well... they will obviously think that I'm hallucinating. (P6)

Even when patients have the courage to share their thoughts about spiritual and existential issues, and are able to do it in a way that is not interpreted as symptoms by professionals, they might perceive that they are *not being taken seriously* and that the staff are only interested in talking about mental illness. Spiritual issues appear as a 'no-go zone', as 'one is not allowed to talk about such things' (P1). This is a source of frustration and gives rise to reflections about psychiatric care being insufficient as professionals fail to approach what is important in an appropriate way.

When you come to psychiatry, (---) they are so focused on everything, almost every thought you have, being an illness. But that is wrong. Everybody has existential questions that they carry with them. (P5)

From patients' perspectives, professionals tend to ignore their need to share and reflect on spiritual issues. This contributes to the experience of being an outsider, whose understanding of life is too different to share with others. As a result, patients might seek support elsewhere, sometimes from other patients or from outside the hospital, and sometimes in a congregation, or by talking to a priest. Sometimes this too fails, which can leave persons with an experience of *not belonging anywhere*:

I'm not a member of any congregation, and I don't frequently visit the church. I have been very, very active, but I have become so disappointed and hurt in that world too. So, I've become a little..., well I feel a bit singled out for being mentally ill there. I don't feel... what shall I say...at home there, in a strange way. (P11)

Experiences of being an outsider, of not being taken seriously and accounted for in encounters with mental health professionals or people in the congregation, leave the person with an experience of having no other alternatives than *managing on my own*.

So, the most important thing I've found out is that I am not only body, but I am spirit as well. There is something beyond the body, and now I try to find artistic expressions for it.... And to communicate it to others. (P7)

By finding other activities, such as arts and music, it is possible to deal with one's experiences. Artistic

expressions are not only a means of managing one's own experiences and coming closer to God, they also facilitate expressing it in front of others in a way that other people can apprehend without 'putting a label' (P12) based on assumptions of madness on the person.

In contrast to experiences of outsiderness, participants also describe experiences of *becoming appreciated by others*. When patients have the opportunity to narrate their spiritual and existential experiences to mental health professionals, they feel that they are heard, seen and respected as persons. Patients are clear about the role of healthcare professionals.

...listen to what one says, however confusing it sounds. Then one might be able to express what's difficult, put words on it in a way that makes it easier, and move on. Even if it might sound weird and very confusing there is also a truth in it, at least for the one who is experiencing it. And what one is experiencing, if it is for real or not, is not up to others to judge. So, there must be some kind of respect. (P9)

When given space to narrate what one is experiencing, persons do not only explore their spirituality, they also perceive that their experiences and needs are accounted for. Sharing the spiritual word and/or reflecting on existential dilemmas also involves a sense of being validated, included and accepted as a fellow human being, despite being different. Encountering nonjudgemental professionals who show a genuine interest thus contributes to an experience of being valued.

Comprehensive interpretation and reflection on findings

Spiritual and existential experiences are complex phenomena that go beyond religion, even though religious experiences appear as part of them. As previous researchers, we found that spiritual experiences can indeed be a resource contributing to experiences of hope, connectedness, meaning and coherence in life (13-15). However, spiritual experiences can also give rise to doubt, anxiety and feelings of loneliness and hopelessness (16,17). In our findings, these experiences appear as multifaceted and paradoxical, as they might involve fear, outsiderness and doubt as well as feelings of trust, belonging and support. This complexity is understood as reflecting participants' lived experience of spirituality, something one is constantly emerged in. Hence, rather than simply understanding spiritual experiences as being things we 'have' or 'have not', or as 'good' or 'bad', it might be worthwhile to reflect on spirituality as something that is always present in alternate and inter-related forms.

Spirituality has often been linked to 'near-death' experiences (44,45). In this study, participants' experiences could be understood as 'near-life experiences'. This metaphor summarises participants' experiences related to their struggle with issues connected to suffering and health while simultaneously being present in life. Approaching spirituality as 'near-life' experiences rather than 'near-death' experiences, implies their connectedness to health as a dialectical process and in line with an understanding of health as endurable suffering (35-36,46), as well as with recovery as a process related to how people manage problems encountered in life rather than as a result or state (9,47).

The paradoxical nature of these experiences also becomes evident as experiences of connectedness to a guiding, higher power as well as humanity contrasted with experiences of alienation and outsiderness. This dialectical understanding also sheds light on a theme found in a study of the monastery as a caring environment, 'blessed alienation' (48), describing that seemingly odd and strange experiences might also be resources when accepted not only by the person but by others as part of life.

As Wilding et al. (11) describe spiritual experiences might be more intense in periods of mental ill-health, this is in line with our findings, where participants describe how spiritual experience can increase and affect them for good and for worse. Our findings do not illuminate if intense spiritual experiences such as perceiving the presence of something extramundane or doubting the will of God contribute to mental ill health, or if mental ill health increases people's spiritual needs and search for meaning. It might go both ways, but in line with person-centred and recovery-oriented approaches, cause – effect is not the core issue. Rather we need to reflect on the needs of people having these experiences and strive to understand the meaning the person ascribes to them. Following Todres, Galvin and Dahlberg's (49) reflections on 'caring for insiderness', nurses need to challenge assumptions about certain spiritual experiences as being symptoms and others as resources and remain open for the 'otherness' of the person. As demonstrated in the theme struggling for acceptance, this is also sought after by participants, who fear that nurses and other professionals would not take them seriously or even deem them as psychotic symptoms. Rather than taking the risk of being judged by others, people might seek to manage on their own and rely on the extramundane to give them guidance, or hope that they will be able to understand the meaning of their affliction later on even though they are questioning the will of God at the moment.

Nurses' approaches to spiritual experiences as being either irrelevant and thus nothing to seriously account for or as being symptoms is not only in opposition to caring for insiderness, it might also mean that spiritual experiences as resources are overseen. Being allowed to have

experiences that involve contact with another dimension without being questioned can contribute to experiences of recovery (48). Hence, just as mental health and psychiatric nurses take an interest in exploring thoughts and feelings associated with other kinds of experiences, they need to approach spiritual experiences with the same openness. This could reduce the anxiety associated with doubts and difficulties in interpreting the meaning of spiritual experiences described in previous research (18,19). In other words, if patients experience that they can have a connection with the extramundane while simultaneously being able to talk about these experiences with professionals, they can receive the support needed to approach spiritual needs as well as perceived problems related to the expressions their spirituality takes. Thus, accounting for spiritual caring needs is not only a matter of supporting religious practices (50), but also of supporting patients searching for stability, peace and growth while helping them to balance different aspects of their spirituality. Such a dialectical approach can also support recovery, both by empowering the person to use his/her spirituality as a resource and by reducing stigma related to experiences of being different and alienated from others (51).

Methodological considerations

This study aimed to describe lived experiences of spirituality from the perspective of people who have been subject to inpatient psychiatric care and to interpret these experiences from an understanding of health as dialectical. The number of participants (11) is in line with Brinkmann and Kvale's (52) recommendation of 15 ± 10 for this kind of study, and their personal histories with different kinds of mental health problems contributed with rich data. As a result of this, we consider the data as representative.

In line with a phenomenological tradition, we sought to 'bridle' (53) our understandings of the concept 'spirituality' and remain as open as possible for participants' experiences in the interview situation as well as during the interpretative procedures. Thus, the interviewer (first author) did not stipulate for participants what he considered a spiritual experience. This is motivated as we, in line with Verghese (2), believe that such experiences are individual and unique. In this study, it was also evident that participants had previous experiences of not being taken seriously, or even assessed as psychotic, when talking about their spirituality with caregivers. Hence, in our search for an understanding of the meaning of spiritual experience, it is what persons themselves describe as such that is important rather than narrowing the focus in line with a specific definition. This does not mean that the interviewer is a passive recipient of participants' narratives. As Lindseth and Norberg (38) describe the uniqueness of lived experiences calls for specific procedures during the interview in order to support narratives that are as close to the lived experiences as possible and to avoid misunderstandings. This is not only important for the quality of data, but also has ethical implications as participants' vulnerability comes into play (54). Thus the interviewer, who is an experienced mental health nurse as well as interviewer, strived to create a permissive climate and also check his understanding with questions like 'What do you mean with...?', 'Tell me more about...?' and 'How isit to talk about these issues now?'.

In the following analysis, the researchers endeavoured to remain open for participants' lived experiences by avoiding exclusion of narratives about experiences that might not fall within a narrow description. The analysis was not a linear process; rather it moved back and forth between the naïve reading and the structural analysis, constantly keeping the aim of the study in mind. As described by Ricoeur (39,40), this reflects the ongoing movement between the parts and the whole in the text, and also between explanation and understanding. Through oral and written communication between the authors, different understandings of the text were elaborated on before there was consensus about the findings of the study. This does not mean that this is the only possible interpretation, and a text has always multiple meanings. However, by reflecting on the structural analysis in the light of other researchers' findings, we argue that our interpretation is plausible and that the suggestions for clinical implications may demonstrate that the findings can impact psychiatric nursing practice.

Based on these reflections, we claim that the trustworthiness of the study could be understood as related to procedural, communicative, pragmatic and ethical validation (55). In line with these authors, the concept validation draws the attention to an in process commitment to quality rather than making 'definitive statements regarding the absolute and objective 'validity' of specific findings' (55, p. 401).

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Conclusions and clinical implications

As described in the literature, a fear of being either ignored or perceived as more mentally ill than one feels can make people unwilling to seek help from healthcare professionals (5,20). This is not surprising as professionals tend to consider and focus on frightening spiritual experiences as psychotic symptoms (26,27), while positive experiences might be considered as resources y(25). However, from a patient perspective, these experiences are intertwined and a part of life. If psychiatric nurses could approach this complexity and, without being judgemental, explore seemingly positive and negative experiences of spirituality as dialectically related to each other, rather than viewing them as either resources or problems, this could contribute to insiderness care and hopefully also support people who struggle with these experiences to seek help when needed.

Conflict of interests

The authors declare no conflicting interests.

Author contributions

TK involved in planning, recruiting, interviewing and transcription. TK also made suggestions for improving the final manuscript. SR and SM analysed the data and involved in first draft of the article. LWG involved in planning, coordinating, supervision and analysis and final draft of the article.

Ethical approval

The study was approved by the regional ethical board.

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