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Participatory culture and digitally mediated mental well-being practices

KATRIN TIIDENBERG, BERIT RENSER, MARKO UIBU AND RIIN SEEMA

KEY MESSAGE

In Estonia, alternative social media groups fill the gaps created by a lack of resources in the healthcare system; yet, they are outside of the remit of the healthcare system. For many, alternative groups are one of the few spaces where they can talk about topics important to them and find understanding and support. The views shared in these groups can empower individuals, but in doing so, they can both support and undermine their mental health and well-being.
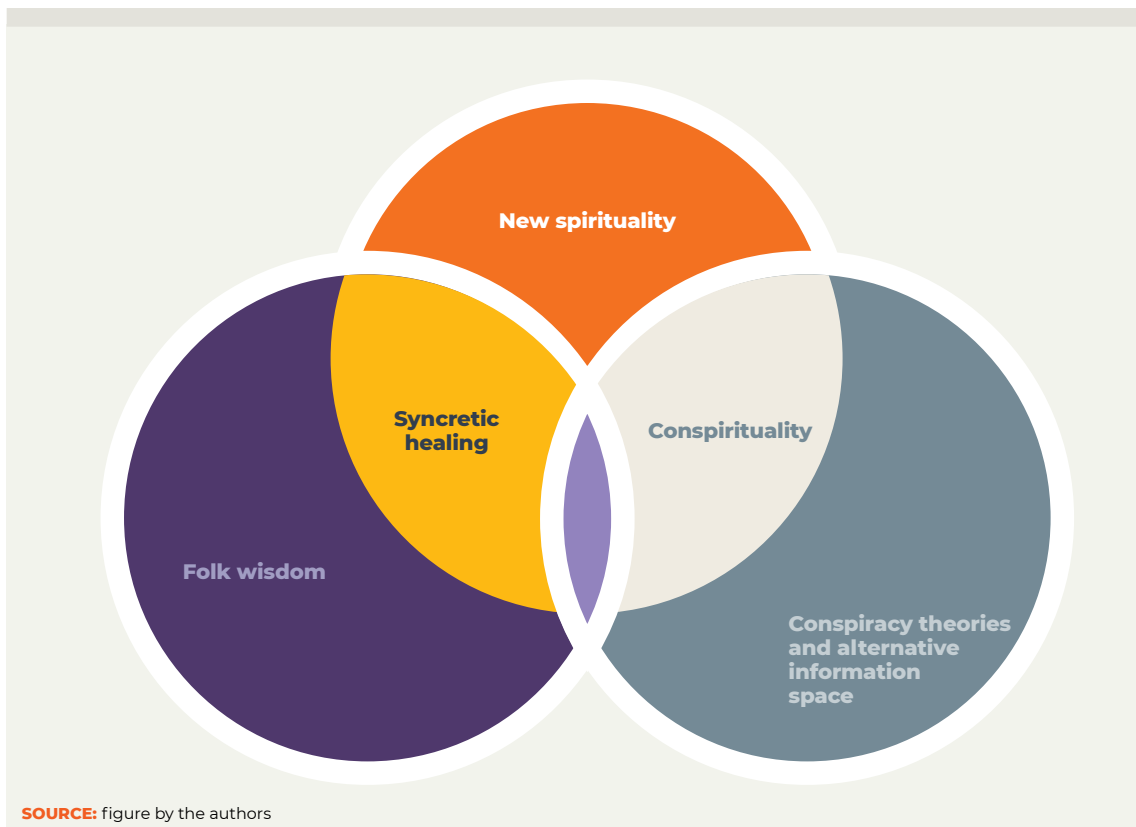
INTRODUCTION

New practices, beliefs, and even technological innovations emerge where the internet meets mental health. This article focuses on informal social media groups that offer alternative interpretations of mental health issues and solutions to them. We use the term 'participatory mental health practices' to describe the interactive, remix-based health and well-being practices enabled and mediated by digital and internet technologies and driven by the logics of participatory culture. These practices are about creating and consuming online content and communicating about mental well-being, including offering support and asking for help. As a result, new relationships, roles and hierarchies emerge between people, as well as new ways of interpreting the world.

Mental-health-related participatory cultures and practices can align with scientific research (e.g. support groups that bring together people with a specific di-agnosis or experience) and thereby support the efforts of health organisations, but there are also plenty of groups that contradict institutional views. This article analyses new-spiritual, conspiritual and folk-wisdom social media groups that are more inclined to create interpretations diverging from institutional views. We use 'alt-interpretive groups' as an umbrella term to describe all these collectively (see Figure 4.2.1 for the links between different alternative interpretations).

'Folk wisdom', which refers to the transgenerational collection of the life experiences of ancestors, is a term familiar to many. However, new spirituality and conspirituality are probably less well known. 'New spirituality' is an umbrella term that includes the more esoteric neo-pagan practices such as witchcraft and shamanism; meditation and mindfulness, which are gaining popularity as science-based in the Western world; and

Figure 4.2.1. The field of alt-interpretive mental health and well-being discussed in this article

New spirituality

Syncretic healing

Conspirituality

Folk wisdom

Conspiracy theories and alternative information space

SOURCE: figure by the authors

reiki and yoga, which blur the boundaries of sports, health behaviour and spirituality. New spirituality is characterised by syncretism, or mixing modern and traditional, spiritual and physical, religious and secular, local and foreign ideas and practices and combining them based on preferences and needs (Uibu 2016). When new spirituality is accompanied by a belief in conspiracy theories and pseudoscience, it is described as 'conspirituality' (from the words 'conspiracy' and 'spirituality'). In the broadest sense, conspiritual groups are united in their opposition to the mainstream.

This article analyses what is happening in alt-interpretive groups from a wider cultural and historical perspective. In doing so, we do not judge the members, activities and beliefs of the groups, as their activity can both support and undermine their mental health. We discuss the implications of participatory mental health practices in alt-interpre-

tive groups and conclude with some suggestions for policymakers, mental health experts and general readers who may be interested in such groups.

Participatory mental health practices in a historical and cultural context

People's choices and the options available to them should always be seen in a cultural, social and historical context Estonia's current vision for mental health considers self-help and community support critically important as a base level of activities and services supporting mental health (see Figure 1.5.1; Randver et al. in Chapter 1).

The Green Paper on Mental Health (Ministry of Social Affairs 2020) defines self-help as activities initiated by the

person themselves, their family or the community (including colleagues) to maintain positive mental health (including learning skills), prevent problems, or promote, improve or restore health (p. 26). In that document, a community is defined as a network of people who are geographically or socially close. Community support could be provided as services by local governments or as informal support by neighbourhood initiatives, village movements and church congregations. Regarding the latter, it is important to note that only 13–16% of the Estonian population report believing in God (Eurobarometer 2005).

Although self-help and community help are mentioned in strategic documents, they are poorly integrated into the institutional system. The Estonian health system is medicine-centred but lacks resources. We lack psychiatrists, clinical psychologists, school psychologists, mental health nurses and general practitioners. The continued stigmatisation of mental health issues is also a barrier to well-being. According to a 2016 survey, 35% of the population agrees with the statement that mental disorders are caused by lacking willpower, and 62% do not want to discuss their mental health problems with anyone (Ministry of Social Affairs 2016).

At the same time, folk medicine continues to be held in high regard in Estonia, and as many as 59% of the population believe in 'a higher power or people with superpowers' (Kantar Emor 2017). The media plays an important role in discussing spiritual, magical and traditional ideas. Healers and witches have been portrayed as heroes since the Soviet era (Kõiva 2015). Even today, media content related to magic and superpowers is extremely popular (Vahter 2018). Considering that Estonians are active internet users, it is not surprising that many such alt-interpretive conversations have largely moved to social media in recent years. The most popular platform in Estonia – Facebook – has hundreds of new-spiritual, conspiritual and folk-wisdom groups, the largest of which have over 30,000 members. We have been investigating groups like these since 2015.

The following statements are based on the analysis of participant observation data, fieldwork notes, about 1,000 posts and 20 in-depth interviews collected over six years. For ethical reasons, we have not mentioned the names of any groups or users and illustrate the research with 'ethnographic mock-ups', which imitate the patterns emerging from the analysis but do not directly reproduce any posts or profiles.

Members of alt-interpretive groups

The membership of alt-interpretive groups is sociodemographically diverse. Although smaller groups may attract people of similar backgrounds (e.g. level of education or gender), differences even out in larger groups, and the broader field of participatory mental health practices on Facebook features a variety of individuals.

Users with greater perceived expertise can become alt-interpretive influencers if they are capable of presenting their ideas in ways suited to the group and the platform and frame them convincingly for the group members (McCosker 2018). Users can achieve expert status by posting actively and continuously, whether they post their opinions or provide assistance. In new-spiritual and folk-wisdom

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Figure 4.2.2. A mock-up profile of an influencer of a new-spiritual public-health group

Emmeline is a beloved adviser in the group Fairy Flights.

She has posted 765 times in five years.

She uses local and global folk beliefs as her source of inspiration, changing, adapting, combining and innovating it as she sees fit.

For her, this is both a job and a mission – while it provides (extra) income, she mainly values it for self-realisation and the chance to help people.

Advisers like Emmeline can self-identify as a sage, psychologist and therapist all in one.

Emmeliine Kunks
Witch, Tarot Queen and Rune Fairy

groups, experts often refer to themselves as witches, healers, sages, shamans, spiritual guides and the like. When advising and helping people, they rely on naturopathy, personal experiences, and magical techniques such as using a pendulum or card reading (see Figure 4.2.2). Simultaneously, they offer their products, services and advice in public groups and in private channels (Facebook Messenger, Skype, Zoom, WhatsApp, by phone or in home visits).

The 'experts' in new-spiritual groups mainly stand out by sharing folk wisdom and giving advice. In conspiritual groups, however, members who offer novel explanations for societal developments achieve a higher status. By posting online, they hope to achieve recognition as (paid) counsellors or coaches, organise courses, publish self-help books, and sometimes break into the mainstream media. The latter aids in further expanding the scope of conspiritual ideas (see Figure 4.2.3).

Social media has been associated with both a more democratic participatory culture and the spread of misinformation because unlike in centralised media, participation is not regulated. However, alt-interpretive groups have a new type of influential gatekeeper: group administrators. They shape the discussion with Facebook's content management tools, which allow them to remove content, accept new members, set rules and enforce them at their discretion.

Figure 4.2.3. A mock-up profile of an influencer in a conspiritual group

Kevin D. P. S. Tate
Shepherd.
WAKE UP!
OPEN YOUR EYES!

Kevin is an opinion leader in the group Ghosts in the Cellar.

In two years, he has turned his social media popularity into a business, organising training courses and concerts and publishing books.

Kevin is convinced that behind every social problem is a small group of puppeteers, whom he calls the 'deep state', who manipulate people.

Kevin exposes the evil deep state in the context of various social events and crises, from same-sex marriage to coronavirus vaccinations and rising electricity prices.

Charismatic opinion leaders like Kevin have the capacity to unite lonely people, who are often seen as 'weird' by others, by giving them a sense of belonging and offering simple culprits and solutions to complex problems.

What are people looking for in alt-interpretive groups and why?

People come to new-spiritual, conspiritual and folk-wisdom social-media groups for different reasons. Reasons for joining include interest in alternative or existential topics, shifts toward particular lifestyles or values, significant life events, and the desire for self-development and growth. Dissatisfaction with the prevailing social order, a feeling of loneliness and missing out, and a lack of trust in the mainstream, be it institutional medicine, science, media or government, can also be motivators for joining. People's interest and willingness to participate, and their acceptance of the meanings and values in these groups, can develop gradually.

In more practical cases, people are driven to these groups by specific concerns or questions. Therefore, people seek solutions to a wide range of questions directly or indirectly related to mental well-being: relationship problems, grief, professional failures, workplace bullying or illness. Users of

new-spiritual and folk-wisdom groups also seek to predict the future and interpret signs of the spiritual world. Sometimes their problems are directly related to mental health. They might complain about depression, anxiety, loneliness and feelings of inferiority. In other cases, it is a matter of a long-term lack of well-being and multifaceted problems. For example, a person may approach the group with concerns that they are experiencing hair loss, but only through a dialogue with the helpers is it revealed that the health problem is due to long-term stress caused by family quarrels and a cut in income.

The size of the group and the number of people offering help are important for those seeking help. As a result of the network effect, answers are faster, more varied and more flexible in large groups than when asking friends and relatives one by one. The diversity of suggestions means that a person complaining about anxiety or domestic violence may be advised to go to a support centre or talk to a psychologist,

solve their problems by smiling, forgiving or being grateful, or have a curse or evil eye removed by a group expert.

For many members, the alt-interpretive groups studied here are one of the few places where they can openly talk about topics important to them, experience support and feel valued. However, social media does not offer belonging and support only to those struggling with (mental) health and relationships. People who distrust authorities, including state institutions, science and medicine, also gather in these groups. A sense of belonging fosters a faster and deeper acceptance of alternative ideas. This explains the development of felt truths that are not scientifically supported but are perceived as true.

Alt-interpretive mental health

Alt-interpretive groups have developed their own systems of meaning, communication styles and symbols, which are based on the idea of awakening. Holism, harmony and ascribing meaning to everything are the dominant tropes in new-spiritual groups. As a result of such a value system, mental health problems are seen more as a developmental challenge and a natural aspect of awakening. Folk-wisdom groups, on the other hand, are more likely to describe both problems and solutions via referring to external factors. Thus, a mental health problem could be caused by the moon, aquifers or a curse, and wearing a red ribbon, plants or crystals

SOCIAL MEDIA AND MENTAL HEALTH

Social media allows charismatic individuals familiar with the platform's possibilities to find a much wider audience than before. Moreover, the status achieved in social media creates a false consensus among members, whereby people with marginal ideas that have received some attention begin to feel that a much larger number of people agree with them than actually do. Social media also favours the deepening of extreme views because of people's desire for continued attention.

Although people with lower levels of education, health literacy and trust in medicine are more vulnerable to health disinformation, the sharing and believing in disinformation is largely driven by a sense of belonging. People circulate content because of the status of the original poster and their own desire to be seen as a certain kind of person by association. Therefore, according to the latest studies, emotional intelligence safeguards against disinformation and helps people recognise manipulative content and analyse their own reactions and the reasons for them.

SOURCES: Schulz et al. 2020; Preston et al 2021

can help. Attributing agency to objects and natural phenomena makes it possible, on the one hand, to justify difficulties and, on the other hand, to see those difficulties as valuable lessons on the path of spiritual development and awakening.

Also, helpful angels or spirits can be positioned as the real actors. These angel groups mostly use the 'language of kindness': members are not criticised or attacked but are given support and encouragement to overcome difficulties (see Figure 4.2.4). Although people who do not believe in angels might roll their eyes at this point, the language of kindness is an important part of emotional support and thus mental well-being.

Conspiritual groups also see connections everywhere but tend to explain these with secret agreements and manipulations rather than holistic unity. They build solidarity using the language of exposing and criticising conspiracies, not kindness and love. Conspiritual solidarity on social media often turns into a

crusade: calls for resistance and exposing the corrupt elite are frequent. However, these groups also talk about 'awakening' and 'becoming aware', which are hoped to bring positive changes.

Social media – a help and a hindrance for mental health

Participation in social media can simultaneously support and undermine mental health. Some initially supportive and empowering beliefs and

Alt-interpretive groups have developed their own systems of meaning, communication styles and symbols, which are based on the idea of awakening.

Figure 4.2.4. Mock-up post from a thread of kindness titled 'Kallistamine' (Hugging), which had close to a thousand similar posts. The colourful animated emojis used in the forum's posts usually depict hugs, angels and hearts
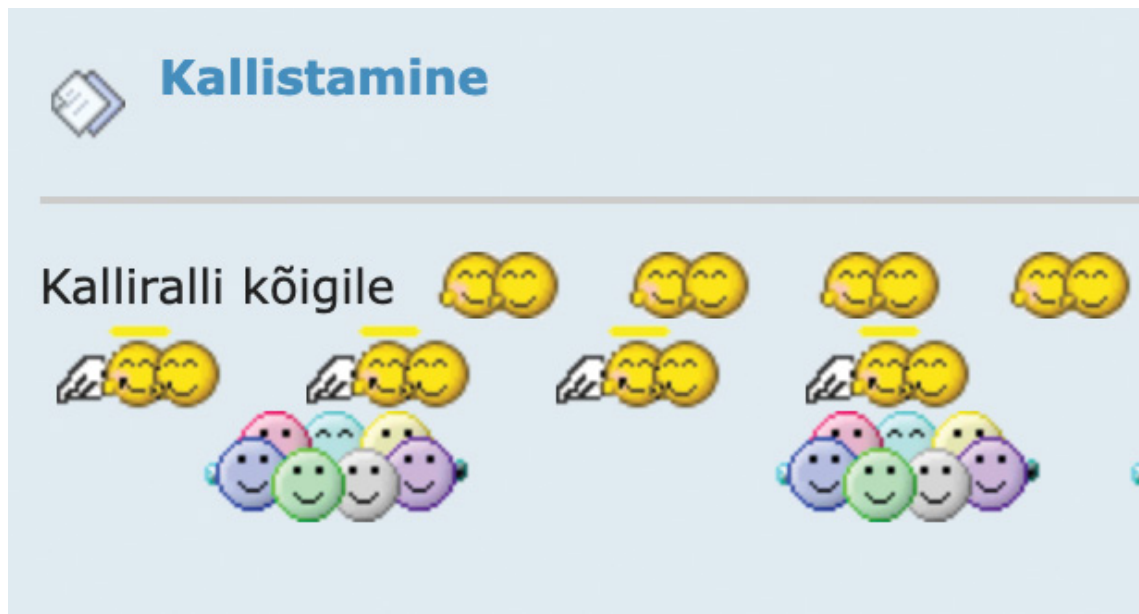
practices may become a health risk. In other cases, group participation is empowering for the individual but harmful to social well-being. We will highlight both the supporting aspects and the problematic aspects as dialectical pairs that best describe the complex reality.

More support can create ideological bubbles and tension

Finding people who think about and have gone through the same things offers social and spiritual support. In all alt-interpretive groups, problems are discussed mainly through personal experiences. This destigmatises problems and talking about them. Finding people with similar experiences helps relieve tension, gives hope and boosts mental well-being in the short term. Conspiritual groups, where members share a sense of disenfranchisement, perceived inequality, distrust of the elite and general alienation from society, also boost members' self-esteem by ridiculing 'the sheeple' and 'the elite'. In these groups, a deep sense of community often leads to activism and even political participation. Most sociological and political accounts of democracy would call this a positive development.

However, the activism of conspiritual groups is often destructive and based on disinformation. The more important group membership is to an individual's mental health and sense of self, the more likely members are to isolate into ideological bubbles. Depending on the group's beliefs, this may result in the development of parallel structures in various areas of life, hindering the functioning of society as a whole. Examples from the recent state of emergency during the pandemic include 'vaccine-free' kindergartens and lawyers handling complaints based on conspiracy theories.

Social media participation can simultaneously support and undermine mental health.

Increased agency is accompanied by reduced privacy and safety risks

Alt-interpretive groups offer many people an opportunity for self-expression that they do not have elsewhere. This has an empowering effect on people, as it teaches introspection, self-analysis and taking responsibility for one's (health) behaviour by observing the experiences and stories of others.

Facebook is built to encourage people to post more and more and to share their private lives; it does this through the user interface, algorithms, and its content management rules and their implementation (see Tiidenberg 2017). In support groups, people are even more inclined to talk about themselves publicly, as sharing more information about themselves leads to better advice. However, many do not realise the reach of their posts or the amount of shared information when all pieces are put together. Public posts that suggest the poster is struggling with poor mental health can also attract those who seek to take advantage of people in need, for example, by offering loans or miracle cures or lifting a curse (see Renser and Tiidenberg 2020). The information shared in groups is controlled to some extent by group administrators and fellow group members, who can warn others. However, due to more active content management by the platform in the context of COVID-19, more and more disinformation and dubious promises move to private conversations, where those in need are even more vulnerable to manipulators.

> **Public posts that suggest the poster is struggling with poor mental health can also attract those who seek to take advantage of people in need.**

Diverse and widely available information leads to the spread of unscientific 'felt truths'

Informal online communities increase the availability and diversity of (mental) health information, mainly in the form of personal stories, which is why such groups serve as a source of information and learning. At the same time, the overabundance of online information and the possibility for multiple interpretations can place people in a maze of information or direct them to 'felt truths' – that is, emotionally resonant disinformation that helps avoid cognitive overload. On social media, people in need receive advice from amateurs without professional training, who draw on tradition, alternative medicine, or, purportedly, messages from the angels or the universe. Sometimes these amateurs are helpful, but it can also happen that those in need of professional help go without it for too long, or the person in need no longer believes the experts because their advice clashes with the alternative interpretation.

SUMMARY

The popularity of alt-interpretive groups reflects the unmet needs of a large segment of the population for belonging, support, being understood and cared for, self-realisation and spirituality. However, alt-interpretive groups have contradictory implications on the individual and the collective level, and these can change over time.

In the short term, this kind of involvement often supports the individual's mental health. The groups fill the gaps created by the shortage of mental health professionals, evidence-based self-help and community-based services in Estonia. From the individual's perspective, increased agency, a sense of belonging and finding support, and easier access to diverse information reflecting life experiences can be considered positive.

In the long run, however, alt-interpretive groups can harm both individual well-being and social solidarity. The spread of pseudoscience and disinformation in alt-interpretive groups is dangerous, and sometimes amounts to antisocial activism. People with mental health problems can therefore miss out on professional help, and in the worst case, their condition can deteriorate to the point where the person becomes a threat to themselves or others. Participation in groups also carries privacy and safety risks, and people in need may be exploited. Isolating into ideological bubbles and the accompanying polarisation can also be dangerous at the societal level.

However, it is important to keep in mind that what we have discussed here is only a part of participatory mental health practices. Due to insufficient data for Estonia, we could not discuss the more professional and pro-social examples of participatory practices, such as web-based mindfulness apps.

Finally, here are some recommendations for policymakers, mental health professionals and also general readers who may join or be interested in groups such as those discussed above.

● It is important to increase access to science-based support services linked to self-help or community help, both online and in the physical environment (e.g. experience counselling or group discussions in local centres, mobile applications, initiatives such as Peaasi.ee and Vaikuseminutid in Estonia). We know from international experience that professionally initiated and moderated social media groups and online portals can also become centres of self-help and community help. Professional mental health help or crisis counselling should be quickly available for people in difficult situations.

● To avoid the spread of misinformation, mental health influencers and gatekeepers active in social media (e.g. administrators and moderators of folk-wisdom groups) could receive training and be involved in health campaigns.

In the short term, involvement in alt-interpretive groups often supports the individual's mental health. In the long run, however, alt-interpretive groups can harm both individual well-being and social solidarity. People with mental health problems can therefore miss out on science-based help, and in the worst case, their condition can deteriorate to the point where the person becomes a threat to themselves or others.

- One option worth considering would be to incorporate the gatekeepers of the existing alt-interpretive groups into national communication strategies concerning mental health and other such issues. Recognising them as important stakeholders instead of excluding them from mainstream influence might reduce confrontation and encourage dialogue.

- Mental health professionals should be aware that such groups exist and can have a significant and often multifaceted influence on people's healthcare decisions.

- Communication guidelines should be developed for mental health professionals to help them engage in dialogue and counsel patients who believe in alternative interpretations and make healthcare decisions based on them, including those who refuse treatment.

- The curricula of general education schools should place greater emphasis on the development of self-awareness, self-regulation and empathy for the sake of both stronger mental health and more competent online behaviour.

- Avoiding stigmatisation and building bridges should be one of the goals of mental health communication in the public sector.

- As members of participatory and alt-interpretive groups make up a significant part of the Estonian population, it is necessary to invest in specific research to understand the dynamics of these groups and facilitate dialogue between scientific and alternative interpretations.

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