Tilburg University

Using experience sampling methods to support clinical management of psychosis

de Thurah, Lena; Kiekens, Glenn; Sips, Rob; Teixeira, Ana; Kasanova, Zuzana; Myin-Germeys, Inez

Using Experience Sampling Methods to support clinical management of psychosis: The perspective of people with lived experience

Lena de Thurah [a], Glenn Kiekens [a,b,*], Rob Sips [a], Ana Teixeira [a], Zuzana Kasanova [c], Inez Myin-Germeys [a]

[a] KU Leuven, Department of Neurosciences, Center for Contextual Psychiatry, Herestraat 49 - box 1029, B-3000 Leuven, Belgium
[b] KU Leuven, Faculty of Psychology and Educational Sciences, Research Unit of Clinical Psychology, Tiensestraat 102 - box 3720, B-3000 Leuven, Belgium
[c] KU Leuven, The Spin-off & Innovation Unit of KU Leuven Research & Development, Waaistraat 6-Box 5105, B-3000 Leuven, Belgium

ARTICLE INFO

ABSTRACT

The Experience sampling method (ESM) has the potential to support person-centered care of psychotic disorders. However, clinical implementation is hampered by a lack of user involvement in the design of ESM tools. This qualitative study explored the perspective of nine people with lived experiences of psychosis. Participants reported a need to monitor a diverse range of daily-life experiences and indicated that ESM should allow for personalization to be clinically useful. While participants recognized the potential of ESM to increase awareness and control over their mental health, concerns were voiced about the validity and burden of monitoring one's own mental health.

1. Introduction

Psychotic disorders are burdensome and require lifetime care and support (Rössler et al., 2005; Thomas et al., 2016). The transition towards recovery-focused care has led to greater treatment engagement and empowerment of service users and improved clinical outcomes (Boardman & Dave, 2020; Dixon et al., 2016). However, mental health professionals and service users often lack the tools to integrate person-centered approaches into practice (Gask & Coventry, 2012; Gondek et al., 2017). The experience sampling method (ESM) enables the collection of detailed information about people's mental health by prompting individuals to complete brief self-assessment questionnaires on their smartphones multiple times daily (Myin-Germeys et al., 2009). By collecting information about mental well-being, ESM can improve awareness and understanding, support service users in making treatment decisions, and facilitate recovery (Myin-Germeys et al., 2018; van Os et al., 2017).

Although often used in research (Myin-Germeys et al., 2009; Mote & Fulford, 2020), ESM is rarely employed in clinical practice. This might be because ESM tools for research purposes do not meet service users' real-life needs and requirements. In addition, a lack of user involvement in the design process often hampers the successful implementation of digital mental health tools in clinical care (Mohr et al., 2017). Although some studies collected user feedback from people with lived experience of psychosis (Hanssen et al., 2020; Palmier-Claus et al., 2013), this has only been used for adaptions of already defined prototypes. Therefore, this study aims to provide a better understanding of the perspectives of people with lived experience regarding the intended use of ESM in clinical practice. To this end, we conducted focus groups with people with lived experience of psychosis to explore what daily-life aspects they consider relevant to assess with ESM. As a secondary objective, we examined general views on how ESM could influence the clinical management of psychosis.

2. Methods

Participants were recruited through service providers and a patient organization. Inclusion criteria were: (a) being at least 18 years, (b) having a schizophrenia spectrum disorder diagnosis, and (c) not having active psychotic symptoms that interfered with the conversational ability and/or orientation at the time of the focus group. Nine individuals between 34 and 54 years old participated, of which six identified as male and three as female. There were 4-5 participants in each focus group, and no one had experience with ESM, although some had

used other types of self-monitoring. All participants provided written informed consent, and the study was approved by SMEC KU Leuven (G-2017 07 851).

The focus group sessions lasted between 90 and 120 minutes and were moderated by two researchers using a short and broad moderation guide (supplementary appendix 1). The researchers opened the sessions by introducing ESM and its application in research. Participants then engaged in an open brainstorming where the moderator used a whiteboard to note participants' ideas and establish commonalities and differences. The focus groups were recorded and transcribed verbatim. We performed a data-driven thematic analysis to ensure the findings reflected participants' experiences (Braun & Clarke, 2006). We first applied open coding using Nvivo 12 (NVivo, 2020). In a second coding cycle, we then generated meta-codes and compiled codes into meaningful themes and sub-themes (Saldana, 2012). The final thematic framework was determined after several peer debriefing sessions with team members (Nowell et al., 2017). Illustrative quotes were translated from Dutch to English (Table 1).

3. Results

3.1. Aspects to monitor with ESM

Participants voiced many daily-life aspects that they perceived as relevant to monitor (Fig. 1.a), which were grouped into four themes; *(1) psychotic symptoms and experiences, (2) moods and emotional states, (3) social functioning,* and *(4) daily-life functioning.*

The presence, frequency, and intensity of psychotic experiences were perceived as primary indicators of relapse and therefore considered relevant to monitor. However, participants' experiences were diverse and highly person-specific. For example, while everyone thought experiences related to *"being out of touch with reality"* were essential to monitor, this included both distressing doubts in one's ability to determine what is real, being steadfast in one's convictions despite others' counterarguments, and having paranoid delusions. *"Having a hyperactive mind"* was another category that encompassed having racing, unmanageable, or associative thoughts (*quote 1*) and coming to sudden groundbreaking insights about the world. A third category concerned *"experiencing strange things,"* such as hearing voices or mindreading. It also included abstract experiences of being in contact with spiritual dimensions or experiencing situations as illogical or unexplainable (*quote 2*). Finally, *"behaving strangely"* was considered relevant such as displaying excessive and impulsive behaviors, making sudden radical life choices, being overly flirtatious, or spontaneously conversing with strangers.

Tracking changes in moods and emotions was the second most discussed theme. *Anxious moods and fear* were important experiences for people with psychosis, including fear of relapse (*quote 3*), fear of "losing control," and feeling unsafe or scared. *Feeling stressed* or overwhelmed was voiced as a potential trigger for psychotic symptoms. Therefore, monitoring sensitivity to environmental stressors (e.g., noisy, busy, or unfamiliar surroundings) was considered highly relevant. Experiencing uncontrollable *intense emotions* such as guilt, shame, despair, or being madly in love was also deemed relevant. Finally, all participants recognized *increased vitality* as a shared experience related to psychosis, such as feeling ecstatic, overly energized, and having an increased libido (*quote 4*). The third theme identified concerns social functioning. Participants found it essential to assess whether someone feels they can *connect with others* and are not socially withdrawing or experiencing *socially stressful situations*. Conflicts with others were particularly important as this reflects that someone is out of balance (*quote 5*). A final theme discussed was people's overall daily functioning, with irregular day rhythms and sleep disturbances considered strong indicators of a decline in mental health (*quote 6*).

Table 1
Quotes for illustration of participants views and experiences.

QUOTE NUMBER	THEME (subtheme)	QUOTE
Quote 1	PSYCHOTIC SYMPTOMS (Hyperactive mind)	***Terry:*** *Yeah, like the way Lucky Luke shoots faster than his shadow, your thoughts can run faster.*
Quote 2	PSYCHOTIC SYMPTOMS (Experiencing strange things)	***Rita:*** *One of the last times I had a psychosis… the hour had changed, and some clocks adjust themselves automatically, others didn't, but I didn't realize the hour had changed. So I woke up and I saw; "It's eleven o'clock," and then ten o'clock in the kitchen and I thought "wooow". And I was completely… "Time goes backward and forward here, I can't follow anymore."*
Quote 3	MOODS AND EMOTIONS (Fear and anxiety)	***Robert:*** *Once you've been institutionalized, you've started a vicious circle. Because you hardly… well, for me anyway… That's so… so terrifying… that you… anything that hints that that could happen again… Yeah then… you really start to freak out. Thinking "Shit, this is going to happen again".*
Quote 4	MOODS AND EMOTIONS (Vitality)	***Terry:*** *In such a state [during a psychosis] you get enormous… that has enormous energetic powers… you get a huge boost and that can express itself in all kinds of aspects, including sexuality.*
Quote 5	SOCIAL FUNCTIONING (Social stress & conflicts)	***David:*** *For me… starting a discussion or something [is relevant to monitor]. At one point I actually got into a discussion with my psychiatrist and then I also said: "Yes, no, what you are saying are authority arguments", and he said: "normally you would never do something like that".*
Quote 6	GENERAL FUNCTIONING (Sleep)	***Simon:*** *…and sleeping… well, if I crawl into bed, and say: "Now I'm going to… sleep all day." Then I'm usually back [in a bad mental state] …*
Quote 7	BENEFITS (Autonomy)	***Ellen:*** *I think the app is a good intermediate step. Like during the period when you don't completely understand how to take care of yourself, to help you understand how you work. And then afterward to be able to continue on your own.*
Quote 8	CONCERNS (Adverse effects)	***Robert:*** *Actually you should do that yourself. You have to learn for yourself [to recognize symptoms] (…) And if you put that [symptom information] in that app, eventually you might be dependent on that app.*
Quote 9	CONCERNS (Burden)	***Robert:*** *That's actually very burdensome isn't it, such an app? If you do that ten times a day? (…) Because while you are walking around with such an app, you are actually trying to recover. Then you actually need all your attention for your… own thing. And then you still have to answer questions?*
Quote 10	FURTHER IMPROVEMENTS (Personalization)	***Charlotte:*** *Yes exactly… that you can enter your own pitfalls in the app, and that it then asks you about those pitfalls.*

3.2. Perspectives on using ESM in practice

Three overall themes emerged in exploring views regarding the use of ESM in clinical practice (Fig. 1.b), which included (1) *benefits,* (2) *concerns,* and (3) *further improvements of ESM tools*. First, participants expected that using ESM could have several benefits, with the *prevention of relapse* via early detection of changes in mental health frequently mentioned. They indicated that ESM tools might help detect subtle
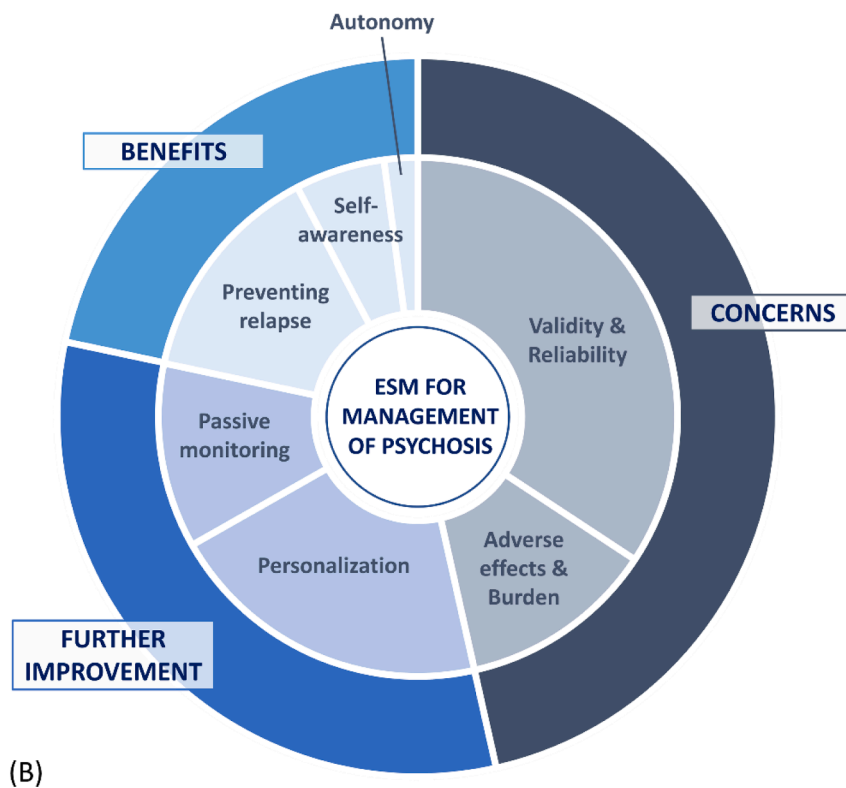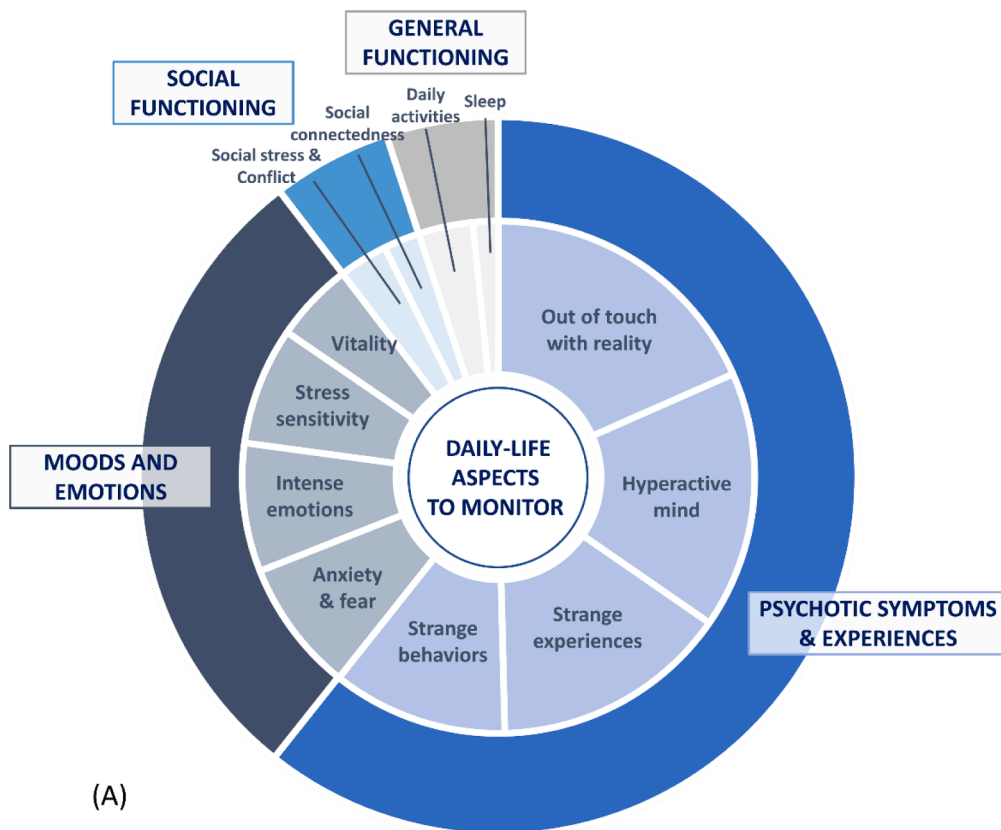
Fig. 1. Overview of main themes (outer circles) and sub-themes (inner circles) concerning (A) the daily-life aspect relevant to monitor for people experiencing psychosis and (B) the use of ESM for clinical management of psychosis, and the proportion of data (number of references) assigned to these in Nvivo.

changes that they could not recognize and could trigger warning messages in response. Some also suggested integrating personal crisis plans to manage acute mental health crises. A second benefit discussed was the opportunity to train *self-awareness*. The frequent self-assessments were considered potentially helpful to enhance awareness and self-insight by making people better at recognizing symptoms and triggers. Finally, a third benefit was believed to be increased control over one's mental health, which could make people more autonomous and less dependent on professional care (*quote 7*). However, several concerns were also voiced. Participants generally agreed that using ESM during acute psychotic episodes could be problematic. They expressed concerns about whether people experiencing acute psychotic symptoms could provide *valid and reliable* answers to the self-assessments. Participants believed that people might provide socially desirable or "fake" answers. This could, for example, be the case for people experiencing paranoia, who would feel that they were "being tested". Participants also expressed concerns regarding potential adverse effects of ESM, including intensifying negative emotions in response to questions and increased smartphone and tool dependency (*quote 8*). Furthermore, they were concerned that the frequent assessments could become *burdensome* (*quote 9*).

A need was voiced to personalize content to increase the potential usefulness of ESM in practice. This could be achieved by allowing users to select or formulate relevant questions (*quote 10*) or allowing algorithms to recognize individual patterns and tailor questionnaires accordingly. In addition, several participants suggested combining ESM with *passive monitoring* of smartphone usage patterns (e.g., time spent on social media) and physiological measures (e.g., heart rate, movement, sleep), which some individuals already had experience with and considered helpful.

4. Discussion

Most ESM research has used fixed sets of researcher-defined questions to assess psychotic experiences. However, our findings show that standard sets of ESM questions might not sufficiently capture all relevant aspects people with psychosis want to monitor. While monitoring psychotic symptoms was considered important due to their enormous impact on people's daily lives, we found an immense variation in individuals' experiences. Furthermore, both negative and positive psychotic experiences were considered relevant, as well as changes in moods and emotions, social functioning, and day-to-day routines. In line with other studies (Bos et al., 2020), people with lived experiences of psychosis considered the opportunity to personalize content crucial to make ESM valuable for mental health management. Developing practical solutions for the personalization of ESM tools will thus be a critical goal in unlocking its potential as a tool to support person-centered care.

Several important benefits and concerns were identified. ESM is believed to hold the potential to support service users by preventing relapse via early warnings and crisis guidance (Palmier-Claus et al., 2013; Terp et al., 2017). Service users also voiced that ESM can help train and improve mental health self-awareness and self-management. Pilot studies found that ESM does increase awareness of symptoms and thoughts in people experiencing psychosis (Palmier-Claus et al., 2013; Smelror et al., 2019). While some perceived this as beneficial, findings also indicate that others might experience adversities from becoming overly aware of negative thoughts and emotions. The burden of ESM is another common concern (Bos et al., 2020; Glenn et al., 2022), and the perceived burden will likely depend on various factors related to the individual user and the tool design. A better understanding of these factors is warranted to tackle issues related to usage burden. Finally, participants expressed skepticism concerning whether self-monitoring is reliable and can generate valid data in people experiencing psychosis. Strategies to assess and increase perceived validity could include integrating objective passive sensor data. Although based on a small sample, our findings voice what people with lived experience of psychosis

consider relevant to monitor with ESM. This information could help guide future efforts toward the actual clinical use of ESM for people with psychosis.

5. Conclusion

People with lived experiences of psychosis consider ESM a potentially useful tool to support them in understanding and managing their mental health. A broad range of daily-life experiences, including but not limited to psychotic symptoms, were considered relevant to monitor. Therefore, ESM tools should allow for personalization to reach its clinical potential. Furthermore, potential barriers, including perceived burden, adverse effects and distrust, must be addressed to facilitate adoption.

CRedit authorship contribution statement

The study was designed by RS in collaboration with ZK and IMG. RS recruited participants and undertook data collection and interview transcription. Interview coding and analysis were undertaken by LT with support from AT. The first manuscript draft was written by LT in collaboration with GK and AT. All authors contributed to the critical review of the manuscript and approved the final version.

Declaration of Competing Interest

No potential conflict of interest was reported by the authors.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.psychres.2023.115207.

References

Boardman, J., Dave, S., 2020. Person-centred care and psychiatry: some key perspectives. BJPsych International 17 (3), 65–68. https://doi.org/10.1192/bji.2020.21.
Bos, F.M., Snippe, E., Bruggeman, R., Doornbos, B., Wichers, M., van der Krieke, L., 2020. Recommendations for the use of long-term experience sampling in bipolar disorder care: a qualitative study of patient and clinician experiences. Int J Bipolar Disord 8 (1), 38. https://doi.org/10.1186/s40345-020-00201-5.
Braun, V., Clarke, V., 2006. Using thematic analysis in psychology. Qualitative Research in Psychology 3 (2), 77–101. https://doi.org/10.1191/1478088706qp063oa.
Dixon, L.B., Holoshitz, Y., Nossel, I., 2016. Treatment engagement of individuals experiencing mental illness: review and update. World Psychiatry 15 (1), 13–20. https://doi.org/10.1002/wps.20306.
Gask, L., Coventry, P., 2012. Person-centred mental health care: the challenge of implementation. Epidemiol Psychiatr Sci 21 (2), 139–144. https://doi.org/10.1017/s2045796012000078.

Glenn, C.R., Kleiman, E.M., Kearns, J.C., Santee, A.C., Esposito, E.C., Conwell, Y., Alpert-Gillis, L.J., 2022. Feasibility and Acceptability of Ecological Momentary Assessment with High-Risk Suicidal Adolescents Following Acute Psychiatric Care. J Clin Child Adolesc Psychol 51 (1), 32–48. https://doi.org/10.1080/15374416.2020.1741377.

Gondek, D., Edbrooke-Childs, J., Velikonja, T., Chapman, L., Saunders, F., Hayes, D., Wolpert, M., 2017. Facilitators and Barriers to Person-centred Care in Child and Young People Mental Health Services: A Systematic Review. Clin Psychol Psychother 24 (4), 870–886. https://doi.org/10.1002/cpp.2052.

Hanssen, E., Balvert, S., Oorschot, M., Borkelmans, K., van Os, J., Delespaul, P., Fett, A. K., 2020. An ecological momentary intervention incorporating personalised feedback to improve symptoms and social functioning in schizophrenia spectrum disorders. Psychiatry Res 284, 112695. https://doi.org/10.1016/j.psychres.2019.112695.

Mohr, D.C., Weingardt, K.R., Reddy, M., Schueller, S.M, 2017. Three Problems With Current Digital Mental Health Research . . . and Three Things We Can Do About Them. Psychiatr Serv 68 (5), 427–429. https://doi.org/10.1176/appi.ps.201600541.

Mote, J., Fulford, D., 2020. Ecological momentary assessment of everyday social experiences of people with schizophrenia: A systematic review. Schizophr Res 216, 56–68. https://doi.org/10.1016/j.schres.2019.10.021.

Myin-Germeys, I., Kasanova, Z., Vaessen, T., Vachon, H., Kirtley, O., Viechtbauer, W., Reininghaus, U., 2018. Experience sampling methodology in mental health research: new insights and technical developments. World Psychiatry 17 (2), 123–132. https://doi.org/10.1002/wps.20513.

Myin-Germeys, I., Oorschot, M., Collip, D., Lataster, J., Delespaul, P., van Os, J., 2009. Experience sampling research in psychopathology: opening the black box of daily life. Psychol Med 39 (9), 1533–1547. https://doi.org/10.1017/s0033291708004947.

Nowell, L.S., Norris, J.M., White, D.E., Moules, N.J., 2017. Thematic Analysis:Striving to Meet the Trustworthiness Criteria. International Journal of Qualitative Methods 16 (1), 1609406917733847. https://doi.org/10.1177/1609406917733847.

NVivo. (2020). (Version 12) QSR International Pty Ltd. https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home.

Palmier-Claus, J.E., Rogers, A., Ainsworth, J., Machin, M., Barrowclough, C., Laverty, L., Barkus, E., Kapur, S., Wykes, T., Lewis, S.W., 2013. Integrating mobile-phone based assessment for psychosis into people's everyday lives and clinical care: a qualitative study. BMC Psychiatry 13 (1), 34. https://doi.org/10.1186/1471-244X-13-34.

Rössler, W., Salize, H.J., van Os, J., Riecher-Rössler, A., 2005. Size of burden of schizophrenia and psychotic disorders. Eur Neuropsychopharmacol 15 (4), 399–409. https://doi.org/10.1016/j.euroneuro.2005.04.009.

Saldana, J., 2012. The Coding Manual for Qualitative Researchers. SAGE Publications. https://books.google.be/books?id=V3tTG4jvgFkC.

Smelror, R.E., Bless, J.J., Hugdahl, K., Agartz, I., 2019. Feasibility and Acceptability of Using a Mobile Phone App for Characterizing Auditory Verbal Hallucinations in Adolescents With Early-Onset Psychosis: Exploratory Study. JMIR Form Res 3 (2), e13882. https://doi.org/10.2196/13882.

Terp, M., Bjørnes, C.D., Jørgensen, R., Mainz, J., Laursen, B.S., 2017. Collaborating with Young Adults Diagnosed with Schizophrenia: A Participatory Design Study to Shape the Healthcare System. Open Journal of Nursing 7, 743–758. https://doi.org/10.4236/ojn.2017.77056.

Thomas, N., Farhall, J., Foley, F., Leitan, N.D., Villagonzalo, K.A., Ladd, E., Nunan, C., Farnan, S., Frankish, R., Smark, T., Rossell, S.L., Sterling, L., Murray, G., Castle, D.J., Kyrios, M., 2016. Promoting Personal Recovery in People with Persisting Psychotic Disorders: Development and Pilot Study of a Novel Digital Intervention. Front Psychiatry 7, 196. https://doi.org/10.3389/fpsyt.2016.00196.

van Os, J., Verhagen, S., Marsman, A., Peeters, F., Bak, M., Marcelis, M., Drukker, M., Reininghaus, U., Jacobs, N., Lataster, T., Simons, C., Lousberg, R., Gülöksüz, S., Leue, C., Groot, P.C., Viechtbauer, W., Delespaul, P., 2017. The experience sampling method as an mHealth tool to support self-monitoring, self-insight, and personalized health care in clinical practice. Depress Anxiety 34 (6), 481–493. https://doi.org/10.1002/da.22647.