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## **Noise as dysappearance: Attuning to a life with type 1 diabetes**

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### **Abstract**

In this article, we use noise as a metaphor for the overload of information - embodied, technological, and online social - that characterizes life with type 1 diabetes. Noise, as an emic and etic term, illustrates embodied sensations of fluctuating blood glucose, measurement problems and alarms from digital self-care devices, and irrelevant or emotionally disturbing posts on Facebook. Attunement is crucial to the quality of self-care achieved by individuals and comprises: 1) developing skills to receive clear signals from the body, 2) adjusting and individualizing self-care technologies to bodies and daily lives, and 3) discerning appropriate distracting and unhelpful self-care information. Ideally, life with type 1 diabetes is balanced, with clear messages from bodies, technologies and Facebook that enable better self-care.

**Keywords:** Type 1 diabetes, Noise, Dysappearance, Attunement, Facebook

## Introduction

On a spring evening in 2016, the first author attended a peer meeting, held once every two months, for adults with type 1 diabetes in a large Danish city. Three men and six women had gathered to discuss issues about their illness; some were participating for the first time, others were already acquainted through Facebook or previous meetings. The meeting had been announced through a Facebook community run entirely by adults with type 1 diabetes. With no predetermined theme, the dialogue among participants drifted between topics related to life with diabetes with which they were currently concerned. In the midst of this calm and relatively quiet environment, Mia, a woman in her 50s, introduced the topic of noise. “Noise, noise, noise,” she proclaimed before continuing, “It is not only the illness that causes noise, it is also Facebook. I just think that there’s a lot of noise, and it’s infuriating.” Mia had an insulin pump and its alarm had just triggered. Mia’s outburst about noise came moments after John, another meeting participant, had to deal with the alarm on his insulin pump. This is noise in its most literal sense, to which one must be attuned in a life with type 1 diabetes.

In truth, Mia’s alarm was somewhat redundant because she had already recognized the symptoms of low blood glucose and taken action, drinking half a carton of apple juice to raise her blood glucose. Hence, she could turn off the alarm on her insulin pump without further thought. In contrast, John’s insulin pump had been triggered by the fact that his blood glucose was too high, a situation that could not be immediately resolved with a sugary drink. John’s alarm had already been triggered three times during the meeting, and its insistent noise was clearly making him agitated. He suddenly stood up, trying to extract the pump from the pocket of his tight-fitting jeans as the shrill alarm continued. He shouted at it to ‘shut it’, as he turned it off with exaggerated movements. At that point, it was hard not to concur with Mia’s assertion that life with diabetes is a life filled with noise. As we shall emphasize, however, one inevitably encounters various types of noise when

living with type 1 diabetes. Although some noises can be muted with an off switch, others do not provide that luxury. Individuals must learn to attune to these noises.

As seen in our initial ethnographic vignette, the idea that life with diabetes is characterized by noise is not merely an analytical conceit; people with diabetes also evoke the concept of noise as a way of characterizing their daily experiences. Susan Sontag (1978) originally highlighted the pervasive nature of metaphor in discussions about illness and disease and her point about metaphor capturing feelings of bemusement and anger is brought to mind in the way people with diabetes talk about noise. The metaphor of noise encapsulates the struggles people with type 1 diabetes experience when practicing self-care at a daily level, a metaphor all the more persuasive for its capacity to seamlessly capture diverse aspects of life with diabetes in Denmark in the 21<sup>st</sup> century.

In our analytical focus on noise in the context of life with type 1 diabetes, we propose a distinction between three types: embodied noise, technological noise, and online social noise. For all three, noise evokes the frequently unpleasant experience of managing information of *indeterminate relevance* from diverse sources, including bodies, self-care technologies, and Facebook.

The concept of noise has emerged in various guises in many disciplines (Novak and Sakakeeny 2015). Although the concept of noise, generally understood as unsolicited sound, may be evaluated neutrally, it is often associated with negative connotations. For example, noise can be defined as a pollutant, with the notion of environmental noise pollution serving as a powerful metaphor for the auditory bombardment to which people are exposed in technology-saturated environments. Studies have found that exposure to noise pollution can lead to symptoms of poor physical and psychological health (Stansfeld and Matheson 2003; Gan *et al.* 2012). More recently, Rice (2013) applied the concept of noise to extensive fieldwork on the practice of auscultation based in a London hospital, describing different kinds of noise stemming from diverse medical

devices, such as monitors, and embodied practices in which augmented listening to bodily sounds, such as heart rate, is an integral aspect of diagnostic practice.

Throughout this article, we attend to aspects of life with type 1 diabetes that are associated with noise, defined here as an overload of unprocessed information that can include embodied noise, technological noise, and the noise of social relations on Facebook. We explore how people with type 1 diabetes develop strategies to differentiate between various daily information inputs, paying particular attention to the practice of diabetes self-care; in other words, we explore how people attune themselves to the noise of type 1 diabetes. Attunement to life with type 1 diabetes requires a range of knowledge, skills, and strategies, which are developed through years of living with the illness (Pols 2010; Mattingly, Grøn, and Meinert 2011; Nielsen and Grøn 2012).

### **Background: Contextualizing self-caring type 1 diabetes in Denmark**

Type 1 and type 2 diabetes pose an alarming public health problem calling for a multifaceted approach to care (Barry *et al.* 2017). Type 1 diabetes is an autoimmune illness in which beta cells in the human pancreas, the body's sole generators of insulin, are attacked and destroyed by the immune system. The body becomes incapable of generating insulin, without which it cannot metabolize its energy intake. Treatment requires daily injections of insulin and vigilant blood glucose monitoring (American Diabetes Association 2013). No cure exists. The chronic, high-maintenance nature of the illness results in a blurred distinction between treatment and life with type 1 diabetes (Mol 2008; Guell 2011). In Denmark, with a total population of around 5.7 million people, approximately 30,000 people are diagnosed with type 1 diabetes. Receiving a diagnosis of a chronic illness such as type 1 diabetes is a major event shaping and reconfiguring all areas of daily life. Funnell and Anderson (2004) claim that the self-care regime for type 1 diabetes is one of the most complicated of all chronic illnesses, due to the highly specialized practices involved in daily management. Self-care involves daily insulin injections by insulin pen or insulin pump, blood

glucose measurements, carbohydrate intake calculations, and changing vials and needles (Coyle, Francis, and Chapman 2013). Patients conduct these practices alone, without direct support from healthcare professionals. After diagnosis, patients must gradually learn and assume responsibility for these practices, a process requiring the development of some degree of mastery over the complex interactions between bodies, biologies, and technologies occurring in the context and course of daily life (Danholt 2013; Mol and Law 2004).

The sheer amount of time required has been stressed in some studies focusing on the demands of diabetes self-care regimes and the use of digital self-care devices (Mol and Law 2004; Mol 2008; Danholt 2013; Guell 2011; Guell 2012; Hernandez 1996). Patient education is offered in a group-based format in Denmark, but it can fail to meet individual needs that arise during the daily practice of self-care (Nielsen and Grøn 2012; Bury 1982). For some patients, the resulting uncertainty about their condition and what is required to achieve and maintain effective self-care leads them to seek out peers in online communities including on social media platforms (Kingod *et al.* 2017).

The emergence of internet technology and social media have facilitated a significant shift in both access to health-related information and the ways in which health information is communicated. Part of this shift is characterized by the spread of horizontal health communication in which patients, peers, and laymen gather and disseminate knowledge without recourse to the expertise of a healthcare professional. Previous studies examining these developments have focused on the empowering effect, or lack thereof, of health-related online communities (Eysenbach *et al.* 2004; Dedding *et al.* 2011; Demiris 2006; Barak, Boniel-Nissim, and Suler 2008). Other studies have focused more narrowly on possible components of empowerment (Sandaunet 2008; Høybye, Johansen, and Tjørnhøj-Thompsen 2005; Mazzoni and Cicognani 2014; Armstrong, Koteyko, and Powell 2012). A few studies have included people with diabetes, their interaction in online

communities, and how the latter are used as a space for reporting personal experiences, asking questions, and receiving direct feedback from peers (Greene *et al.* 2011). To the best of our knowledge, however, no reports focus on the experience of illness-associated noise in daily life with type 1 diabetes.

### **Methodology**

This study is inspired by praxiography, defined as ethnography with a primary focus on practices (Mol 2002). A practice focus examines how people practice self-care, including the interplay between bodies and technologies used for treating the condition (Shove, Pantzar, and Watson 2012). The practices we observed primarily relate to how adults with type 1 diabetes made sense of daily self-care and their strategies for dealing with noise. As a praxiographic study calls for multiple methods adapted to the research design, our aim was to approach online and offline social dimensions as complementary, rather than as distinct and essentially at odds with one another (Bueger 2014; Mol 2002). Any distinction between the two fails to capture the way they are seamlessly incorporated into the daily self-care of adults with type 1 diabetes. Several studies highlight the fact that Web 2.0 and social media apps on smartphones have become embedded, embodied, and everyday technologies (Hine 2015; Miller *et al.* 2016, Kingod *et al.* 2017; Chayko 2008).

Fieldwork was conducted between June 2015 and June 2016. It included a year of observations of interactions within 16 Facebook communities for adults with type 1 diabetes, 12 in-depth interviews, and 6 participant observations at offline peer meetings announced through Facebook. In Denmark, the use of Facebook is widespread among people with type 1 diabetes. Recognizing the extensive amount of activity within Facebook communities, individuals were asked during interviews to list the ones they participated in most. Three type 1 diabetes communities on Facebook with different foci (a larger general community on type 1 diabetes, a community on

insulin pumps, and a community on exercise) were selected for in-depth study on a daily basis, and thirteen other communities were observed more occasionally.

Access to the communities on Facebook for adults with type 1 diabetes was gained during a pilot interview with one of the administrators, who was a founding member of a few online and offline peer communities and meetings. She assisted with identifying other existing communities and was kind enough to upload a post revealing the research aim and the researcher's requested lurking status so as to avoid interfering with the natural online environment (Patton 2002; van Someren *et al.* 1994). The post also served to recruit people for individual interviews, which were conducted to understand how adults with type 1 diabetes integrated Facebook into their daily lives and self-care.

Observations were not restricted to interactions in Facebook communities. They also took place during interviews with individuals who navigated between online and offline domains with a smartphone and well-developed digital dexterity. The aim of individual interviews was to illuminate the integration of online and offline sociality. Interviews were structured to understand daily self-care practices with type 1 diabetes and the use of Facebook for peer support and to provide data on individuals' experiences of using Facebook throughout the day and on how online practices and shared content within communities interfered with daily self-care practices. Interviews were augmented by several informal conversations during and after offline peer meetings, e-mail contact, and phone calls with the same individuals to obtain a deeper understanding of daily life with type 1 diabetes (Dalgas 2016).

Following people with diabetes as they moved seamlessly between online and offline contexts was made somewhat easier by the fact that some participants in the online Facebook groups actively sought to integrate the two. Thus, six participant observations of offline peer meetings also contributed to the data used in our analyses. These meetings were all announced

through the Facebook communities, although they appealed only to people living in relatively close proximity to the meeting location. All interviews and participant observations were anonymized and transcribed verbatim.

### **Embodied noise**

Daily life with type 1 diabetes comprises various noises. While their origins and nature may be diverse, a universal attribute is that they cannot be ignored; these noises demand the attention of the person who is exposed to them. Embodied noise can be exemplified as an experience of an unregulated blood glucose level that requires action on the individual's part for stabilization.

Embodied noise relates to internal signals caused by a faulty pancreas; if this noise goes unnoticed, it intensifies. Untreated, a body that is unable to generate its own insulin will fail to obtain energy from food and begin to metabolize available fat cells. Left unchecked it results in a potentially fatal condition known as ketoacidosis. At the other extreme, treatment with insulin brings its own risks, including hypoglycemia, in which levels of glucose in the blood reach critically low levels and body functions begin to shut down. In its most extreme form, hypoglycemia can lead to coma and death. The nature of these risks means that managing blood glucose is a continuous and critical endeavor for people with type 1 diabetes. High blood glucose over a prolonged period is a proven risk factor for the onset of diabetes complications, whereas repeated instances of hypoglycemia can reduce an individual's awareness of symptoms (Lawton *et al.* 2014). Although the immediate consequences of blood glucose outside the normal range are less obvious than the consequences of the extremes of ketoacidosis and severe hypoglycemia, the uncertain nature of the threat is one of the factors that make living with diabetes a challenge that requires constant vigilance.



Andy exemplifies this vigilance. Despite being 60 years old, Andy was new to life with type 1 diabetes, having been diagnosed little more than a year before. He monitored his blood glucose with a blood glucometer and took insulin on a daily basis, which he injected with a purpose-designed insulin pen. Andy used his glucometer less frequently than recommended by health professionals, in part because he was concerned that the constant pricking of his fingers would cause permanent nerve damage. He was acutely aware of the danger of infrequent blood glucose measurements and explained his strategy as based on developing a sense for the signs of fluctuating blood glucose. Far from neglecting his diabetes, Andy's strategy was one that demanded continual attention to his body. His strategy also required him to be able to identify the symptoms as diabetes-related, which was not always immediately obvious because physical symptoms of low blood glucose, such as fatigue or irritability, are easily conflated with life in general. During a conversation in his home, Andy laid out on the table all the equipment he used for regulating his blood glucose:

"If I am on the wrong side of 8 (blood glucose number in mmol) then I become tired and drowsy. That means that I am aware of my bodily sensation. I measure before I take a run. I take carbohydrates if I am too low, and I always carry an energy bar in my pocket, when I feel that I can use it."

This quote illustrates Andy's need to rely both on his senses and a blood glucose level measured by a device. As he in particular finds it challenging to control his blood glucose level during and after exercise, he measures more often in these instances. How to crack the code of fluctuating blood glucose during and after exercise was a topic that was often brought up and discussed within type 1 diabetes communities on Facebook. Andy's way of 'listening to' or sensing his body is evocative of points highlighted in the study by Rice (2013) on auto-auscultation. In a hospital-based ethnographic study, Rice describes both patients and healthcare professionals as

embodied listeners, a skill mastered over time and through practice. Focusing on patients with heart disease who practice listening to the sound of their hearts, Rice identifies rapid transitions between different types of listening, such as inner listening to a heart rhythm and outer listening to heart rates and intervals detected by technological devices. As with the experiences of people with heart disease recounted by Rice, the case of Andy highlights a potential tension between the full-blown sensory experience of illness and the more restricted, primarily visual, markers of disease status used by healthcare professionals. This potential tension can, in part, be located in what Duden calls 'medicine's visual command performance' (Duden 1993:21), and the fact that visual data are generally valued as more reliable than data derived from other senses. In Rice's ethnography this tension is something which impacts on both patients and healthcare professionals, especially when information acquired from other senses is effectively rendered as either redundant or invalid. Andy is resistant to a self-management strategy that negates his embodied experience of diabetes. This is an approach which requires more vigilance, since it demands a continuous attention to the various signs of fluctuating blood glucose. At the same time, Andy is cognizant of the fact that he can only operate with the self-management strategy he prefers if he is also vigilant with regard to the objective markers of his diabetes status. He is, in other words, continuously striving to achieve harmony between the two.

Embodied noise is exemplified when Andy's blood glucose fluctuated, which he defined as small sounds that would turn into severe alarms without action. Problems arose when it became difficult for him to register the fluctuations. Throughout the day, Andy needed to process data from his body and from numbers, displayed by his self-care technology, because he relied on the technology when his senses failed him. He hoped he could become less reliant on measuring with more practice of attuning to his body. He explained that this was not easy but could be mastered by practicing attention, which was a strategy for him to understand his body and reduce the levels of

experienced noise. He had developed a table, inspired by his peers in Facebook communities, in which he noted the hour of the day, his measured blood glucose level, which he compared with his sensed one, carbohydrates, and exercise. He used this table as a tool to train attunement to his physical condition. Ingold (2011; 1993) describes attunement as knowledge and skills developed by a practice of bodily fine-tuning and attention. It requires strengthening the senses of watching, listening, and feeling (Ingold 1993). Andy ‘listened’ to inner signs of fluctuating blood glucose, which were quiet noises from an out-of-balance body that could easily be confused with less ominous physiological noises arising from hunger, thirst, and fatigue. He had to sort all data from his body to take timely action on a fluctuating blood glucose level.

The sensory experience of blood glucose fluctuation varied among informants. Some could sense a fluctuation close to normal levels (defined by blood glucose levels of 4-8 mmol); others first sensed fluctuations when several bodily alarming sensations such as inner restlessness or agitation indicated a number that was too low or too high. At times, these fluctuations were visible to outsiders through physiological reactions such as sweating, shaking, or talking nonsense, which could only be reversed by consuming carbohydrates to raise blood glucose levels. It was not uncommon for inner alarms to go off several times a week or even many times a day. This had a potentially stigmatizing effect, as individuals with type 1 diabetes were required to momentarily withdraw from their social lives to undertake self-care practices to either raise or lower levels. Tanja 41 year old, who as diagnosed with type 1 diabetes at the age of 21 provided an example of this:

“At times I am forced to take a break, in order to ‘pull out the plug’. This could be a situation where I have to get some sugar, because I suddenly sense that I am rambling. Even though I know that there are people nearby to assist me if necessary, I always carry some sugar around.”

Listening to herself rambling, Tanja experiences what Leder (1990) defined as bodily disappearance, referring to an unwanted consciousness of the body or aspect of the body that occurs during times of disease, distress, or dysfunction. The disappearance of inner embodied noise worked as a useful alarm about the need to address blood glucose levels simultaneously making illness more present in daily life. The study by Maynard (2010) on disability and disappearance when living with cystic fibrosis also describes an unwanted consciousness of the body, which required practices of bodily interpretation.

When Andy practiced listening to or sensing his body, it gave him a sense of control over what happened inside him, which is also why he preferred using an insulin pen, rather than an insulin pump. An insulin pump is attached to the body and provides continuous small amounts of insulin, replicating the actions of a healthy pancreas. With an insulin pump, Andy feared that he might get lazy and lose the skill of listening to his body. The bodily signs, when processed correctly, guided him in regulating his blood glucose.

### **Technological noise**

Using an insulin pen requires a continuous attunement to the body cross-referenced with visual comparisons to the number revealed by the glucometer. Whereas using an insulin pump in combination with a continuous glucose monitor calls for an attunement to the technology because the pump has to be continuously adapted and adjusted to the body it must serve (Winance 2010). Here noise becomes extended from the body to the technology and therefore the strategies of attunement from using a pen to a pump differ.

Newly diagnosed individuals are often more sensitive to fluctuations, whereas a potential side effect of the illness over time is a decreased ability to sense low blood glucose levels, a risk, in other words, that the body is silenced (DeVries, Snoek, and Heine 2004). This distinction was evident within Facebook communities, in which individuals with long-standing type 1 diabetes

searched for ways to regain sensitivity towards the signs of hypoglycemia. When sensitivity to blood glucose levels deteriorates, which in biomedical terms is referred to as ‘hypoglycemia unawareness’, an insulin pump becomes potentially advantageous (Lawton *et al.* 2014). Lisa had been living with type 1 diabetes for more than forty years, diagnosed at the age of 8. She had difficulty sensing her blood glucose levels, so the visible number and alarms on her insulin pump acted as a compass, steering her self-care in the right direction. She downloaded the data on her insulin pump and analyzed it in conjunction with her healthcare practitioner, which allowed her to adjust her insulin pump to her particular needs. Her pump became what Koksvik (2016) has defined as a communicator on behalf of the patient. Koksvik describes fluid relationships between human (patients) and nonhuman (lifesaving machines) actors in which the machine communicates for the patient and the patient also communicates through the machine. Even though Lisa appreciated the machine, she often felt that it was not properly adjusted to her body. In a 2008 study, Mol describes how technologies, daily habits, and people’s skills require mutual adjustment and that the human and the technology have to be attuned to one another (Mol 2008).

Lisa was very interested in finding out how to ‘hack’ and reconfigure her device to make self-care easier, including changing the pump’s annoying alarm to a sound from her smartphone. Changing technology to fit individual needs and lifestyles has been stressed in several studies, from self-tracking technologies (Lupton 2016; Fox 2015) to negotiating and fitting technologies to bodies and daily lives (Winance 2010; Pols 2012). Lisa reflected on how receiving an alarm from her smart phone rather than her insulin pump was less ‘noisy’ because she found the alarm on the pump very disturbing:

“The pump has an interface that just makes me wants to kill it all the time, because I am tired of needing to press on the bottom so many times to silence it! If I hack the

pump I can use a remote function that is more user-friendly and less disturbing for me.”

She had recently considered joining a newly established community on Facebook for practical guidance and information about how to hack her insulin pump and connect it with a smart phone. Membership of this community was growing, and it offered offline meetings with unauthorized tutorials on how to change the technology. However, hacking her insulin pump would only succeed if the accompanying continuous glucose monitor maintained its signal to her insulin pump. Lisa had many examples of how the insulin pump misguided her when the continuous glucose monitor measured her blood glucose level incorrectly, resulting in loud false alarms throughout the day. This technological noise was common among the observed individuals, due to difficulty attaching the monitor properly to the body. Lisa explained how these alarms could sound at all times of day, sometimes in very inconvenient situations.

“It is so frustrating when the alarm goes off several times, and I have to get it from underneath my shirt. And it just keeps going off. Stupid pump!!”

Rice (2013) describes technological sounds as offering patients a way to ‘hear’ or imagine what is taking place inside their bodies. Even though Lisa appreciated the assessment of her blood glucose level, the insulin pump with its noisy alarms often also made her illness too present. The noise of the alarm was not congruent with the state it was indicating, or at least with Lisa’s subjective experience of this state. Confronted with a quieted body, people with diabetes become more reliant on technological surrogates, yet these surrogates tend to be relatively crude communicators. This was particularly evident when the technology malfunctioned or the insulin pump was not properly adjusted to the body it was intended to serve. As a pump user, it is necessary to make continuous adjustments of insulin doses in order to respond to internal and external factors affecting blood glucose. Too many false reminders from malfunctioning technology are

counterproductive, creating a negative awareness of illness as more present than usual. In a study on telecare, Pols (2012) reports that a device reminding someone of their illness is beneficial, but it should not make the illness take up too much space. Despite her frustration with the pump, Lisa noted that it was sometimes even worse when the pump did not sound an alarm and she recognized that relying on sensory input from her own body was no longer an option, since by the time she could sense these signs it was generally too late, with symptoms, such as shaking hands, sweating, dizziness, and speaking nonsense also visually apparent to others.

Even though Lisa had been living most of her life with type 1 diabetes and Andy had been diagnosed just the year before, they both regularly felt lost about how to self-care in specific situations. In general, adults with type 1 diabetes have approximately four annual visits with healthcare professionals, primarily dedicated to numbers-based routinized biomedical practices (measuring blood glucose and blood pressure, weight, vitamin and mineral levels, and eyesight). These visits rarely provide knowledge about how to manage type 1 diabetes in various situations that occur in daily life. The need for comprehensive daily self-care practices drove informants to Facebook to find guidance and support about how to silence unwanted illness-associated noise.

### **Online social noise**

The informants in this study were members of several Facebook communities and interacted in them to varying degrees. Enrolling in Facebook communities was a strategy to solicit guidance and support, to address doubt and decrease an unwanted focus on the illness. The amount of data from these communities was, however, often overwhelming, causing the opposite effect. When this occurred, Facebook became another device to operate and another source of noise.

When confronted with instances of the embodied and technological noise described here, informants often approached peers on Facebook with questions. However, noise also appeared online. An overload of irrelevant or emotionally disturbing information could occur, especially

among people not used to navigating Facebook, who lacked familiarity with the search functions provided by the platform. Selecting particular communities targeting specific aspects of individual self-care was a strategy to reduce the noise caused by information overload.

To use this strategy, individuals first had to find the right communities for their specific self-care needs and regimens; e.g., insulin pump users posted most actively in communities targeting their specific brand of insulin pump. The multiplicity of communities reflected various methods of self-caring for type 1 diabetes. Conversely, even though the observed individuals were selective about the communities in which they participated, they still often felt flooded with information. Continual smart phone notifications about community activity increased the focus on illness to the point where informants felt a great deal of time was required to sort out wheat from chaff in terms of their individual information needs.

Although they experienced Facebook as a quick and easy way to receive essential experiential knowledge on how to live with illness, study informants needed to understand the site's platform, options and communities' netiquette before Facebook could be truly supportive. Observations of their interactions with the technology revealed that the informants both created and received noise. This was evident when information and questions were posted in the wrong communities or when individuals did not understand platform functions. For example, when questions about insulin pens were posted in the insulin pump communities, members of those communities directed these posts to the larger and more general communities. Irrelevant information sometimes resulted when individuals were unaware of Facebook functions or how to use them within the communities. For example, they often created a post about a question or concern without either using the search function or scrolling through previous content to see if others had already raised the issue. This type of online navigation generated unnecessary confusion



and frustration and caused an unwanted awareness on the illness, here exemplified by the informant Susan:

“It is the proportion. It is like you get the same question 10.000 times. It is usually something like, ‘I am high in the morning’ ...then some of the old ones writes back, ‘try to use the search field.’” (Susan, living with type 1 diabetes for 24 years)

The noise generated by many similar posts throughout the day caused people to withdraw from the larger general communities into newly established communities, which were more specialized. Even though there was often an introductory guideline explaining how to interact within a community, people tended to neglect it. Often, experienced members would post within communities about appropriate netiquette:

“....The fact that the same information is posted all the time makes the threads unnecessarily long. There is the risk that concrete and useful information is drowned out. I have often looked for answers that I almost couldn’t find because of all the ‘noise’. I wish that people would just browse through the information...I just wish for shorter and clearer threads.” (A woman who created a post that received 57 replies)

This post illustrates the problem of noise. This issue was developed further during a conversation with Anna in which she addressed the noise of irrelevant replies to her question:

“A thread tends to develop and then so much irrelevant information is posted. You know, just to give an example, of a community on food and type 1 diabetes. I am vegan and there are not a lot of vegans. Then I ask, is this also a vegan group? And then I get 7000 replies (exaggerating). The first replies are typically a ‘yes’ or a ‘no’ and then it develops into ‘I don’t like this’ or ‘I eat this and this’ ...In this way there is suddenly so much information about something completely different. And it was not what I asked about initially. And then I just sit there and I am tempted to scream

out: ‘JUST READ MY QUESTION!’” (Anna 36 years old, and living with type 1 diabetes since she was 14 year old)

Anna joined the Facebook communities to find solutions to specific concerns that would make her self-care easier and make her illness stay in the shadows instead of being in the foreground all the time. However, she often felt that she received irrelevant replies to her questions, which tended to develop into other topics; she then felt more lost than when she initially posted the question. Rice and Katz (2001) note that online information-searching skills must be learned. Every online platform requires an understanding of how to navigate within it. It was evident that not all informants were equally skilled in sorting out the information within the Facebook communities. Another informant, Susan who was diagnosed just three years ago at the age of 50, elaborated on how she had to filter the posts online:

“It is all about being able to sort out, so you won’t drown. If you have to relate to everything, then you get stressed. In some groups, however not these ones, you can only like the content, and then you have to search for your information. But in our groups, we share everything and then you have to be able to filter/sort out the posts.”

Susan used the strong metaphor of drowning to illustrate the massive amounts of information circulating within the communities. However, she would have rather filtered the information than not receive any. She described how, over time, she learned to navigate within the communities to find specific information, which included using Facebook functions such as the search option and knowing whom to contact for the right peer advice. For some informants, managing noise required filtering information and finding the right peer community—and also periodically withdrawing from the community:

“It is like...if I have a period in my life where the illness takes up too much space, then I ignore it...then I don’t read it. And when I am on top of it, or think that I can handle my illness or when I feel that I can overcome it or just need it. It also differs when I feel that I need it. It is not the same for me. I can need it in periods where I either feel it is difficult to control or when I feel on top of it. It can take up too much space in periods.”

(Anna)

Another area identified with online social noise related to posts with an emotionally disturbing effect. These posts primarily included information about late complications such as nerve damage, retinopathy, kidney disease, or foot problems as side effects of high blood glucose over time (Steffens and Anderson 2013). This finding is consistent with a study among women with breast cancer who withdrew from an online community to avoid painful and anxiety-provoking information (Sandaunet 2008). Studies have shown a tendency for participants to manage noise by seeking affirming information online, fostering hope instead of fear (Kaufman and Whitehead 2016; van Uden-Kraan *et al.* 2008; Radin 2006). The Facebook communities observed in this study often identified desirable content in introductory comments about community netiquette on the welcome page. Some communities emphasized strong emotional support and free sharing of difficult stories about illness; others aimed to empower individuals through a decreased focus on the negative aspects of the illness and an increased focus on empowering messages, borrowing from positive psychology. Lisa explained how she established a more empowering community in response to a general community in which she was exposed to stories of late complications, often combined with uploaded photos of foot wounds. This made it more difficult for her to cope with her illness:

“I think that most people with type 1 diabetes want it to take up as little space as possible. It is like now when we talk, I don’t want to only sit in a diabetes energy. Because it is very difficult to talk about all the time, I can tell you. I would break down.

It becomes too much diabetes...I like to have access to information, but not to the posts that are disempowering.” (Lisa)

Noise, related to what Lisa defined as disempowering information, caused the illness to stay in the foreground. “Too much diabetes”, with a focus on the many severe and negative side effects, strained her ability to cope with her illness.

## **Conclusion**

### *Attuning to a life with illness*

In this article, we have shown that adults with type 1 diabetes use different strategies when attuning to illness-associated noise that causes an unwanted augmentation of the focus on illness. Dampening noise in one area of life may create more noise in others, underlining the pervasive nature of noise as a metaphor to organize understanding of life with diabetes. We developed a conceptual definition of embodied, technological, and online social noise; each type of noise requires distinct strategies that share a common focus on attunement that enable individuals to filter out information that is neither relevant nor helpful. For individuals who live with type 1 diabetes, noise is unavoidable, and the study informants tried a variety of practices to fine-tune themselves to a life with type 1 diabetes including sensing bodies, adjusting technologies and filtering social media data.

The metaphor of noise is pervasive and certainly captures something of the mystical or dangerous aspects of diabetes as an illness (cf. Sontag 1978). Yet while the noise may be said to have generally negative connotations, it is not something which can be ignored and in certain respects people with diabetes appear drawn towards the noises that they encounter. Living with a body that has been muted, people with type 1 diabetes are drawn towards devices that replace subtle embodied signals with crude alarms. Thus the concept of noise poses a paradox, because it is both desirable and unwanted. The informants expressed a desire for information, but exposure to

information overload could lead to the unwanted consequence of disappearance bringing the illness to the foreground of daily life. Nevertheless, when informants could process data from bodies, technologies, and Facebook to receive a clear signal, noise changed into useful information. This paradox also highlights the fact that type 1 diabetes causes unwanted noise, but the noise can also contribute to self-management when individuals can 'tune in' what is taking place inside the body and then apply correct practical knowledge to deal with it. The process of attunement was adapted to bodies, technologies and Facebook, which required continuous development of skills and effective practices. Even though processes and practices of attunement were seen to be individualized and situated they had generalizable elements that could be shared among peers on Facebook.

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