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Everyday managing and living with autoimmune Addison's disease: Exploring experiences using photovoice methods

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ABSTRACT

People with rare diseases are a minority group that faces risks for healthcare and work inequities because knowledge and resources on how to systematically support health or working life are limited. Integrating voices of persons living with rare diseases are an important aspect in inclusive and relevant healthcare practices. This study sought to actively involve persons with autoimmune Addison's disease (AAD), a rare condition, in exploring challenges and possibilities situated in everyday life. Photovoice methods were utilized to incorporate experiences through photographic documentation and group discussions with five persons over seven weeks. Data generated from group sessions were visually analyzed or transcribed and analyzed with thematic analysis. Five themes emerged: Individual and fine tuning in everyday life; It is not how it was; The power of knowledge and support; Becoming the expert in an uncertain context; and, Finding balance and paving new ways. The findings showed that everyday life with AAD was more complex than earlier portrayed; entailing several barriers and negotiations. In order to meet the needs of persons with AAD, more extensive and relevant information, support and self-management education is needed. Moreover, a complementary focus on everyday life to promote their health and wellbeing is also important.

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Introduction

Photovoice offers an approach to involve and engage people as experts in their own lives and provides methods that can generate innovative forums for dialog [1]. This is particularly potent in cases where a community is facing marginalization as a result of not having their voice represented. People who carry out their everyday lives with rare diseases are not only a minority group by definition, but can face risks for healthcare and work inequities; because knowledge about how to systematically support health, working life and participation in the community can be insufficient [2,3]. Integrating the voices of persons living with rare diseases are an important aspect in inclusive and relevant healthcare practices. Photovoice in this study actively involves persons with Autoimmune Addison's disease (AAD) in identifying important aspects in everyday life [1,4].

AAD is a rare autoimmune disorder that can occur as part of a polyendocrine syndrome (with other diseases present), or as only AAD [5]. In AAD, the adrenal glands lose their ability to produce essential hormones, which control several life-upholding systems in the body. Consequently, persons with AAD need lifelong replacement therapies, usually consisting of several individual daily doses of medicine [6]. Adjustments of these medicines from day to day can also be necessary due to internal or external occurrences (e.g. infections or stress). However, there is little agreement about the degree to which medications alone can impact quality of life and life expectancy with AAD [7]. To this date, research has mainly focused on a medical perspective regarding AAD and knowledge is very limited about experiences of what and how AAD impacts a person's everyday life. However, research about AAD indicates

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that the disease can extensively affect a person's experiences of both physical and working ability as well as psychological wellbeing [8–11]. The treatment is also suboptimal in that it fails to fully mimic the body's own hormone secretion [12], resulting in periods of very high and very low cortisol levels. This might relate to limitations seen in terms of working capacity, increased rates of sick leave and disability benefits, and early retirement in persons with AAD. However, research is limited and can only give an indication. Moreover, there is limited knowledge about health promotion strategies and secondary and tertiary prevention in relation to AAD. In the context of AAD, prevention refers to prevention of acute and life threatening adrenal crises, comorbidities, and other health risks.

In order to create new directions in research and healthcare and community initiatives regarding AAD it is important to generate knowledge about relevant aspects in everyday life with AAD. The aim of this study is therefore to generate knowledge about challenges and possibilities situated in everyday life with AAD, by fully engaging persons with AAD in the research process as experts. Research questions included: What aspects in everyday life with AAD are important? What possibilities and challenges do persons with AAD experience in everyday life?

Methods

Background to photovoice methods

Photovoice is a community-based participatory approach that can be used in both research and public partnerships in order to raise awareness about potential inequities [13,14]. Moreover, photovoice is well aligned with questions where an occupational perspective is explicit [1,15]. The methods integrate glimpses of everyday life over time. Members of a photovoice group can do things on their own and together, meet on a regular basis to share, and begin to create future scenarios that rest on occupational potentialities [14]. The photovoice method (PVM), as in this study, invites individuals to reflect on barriers and facilitators in their community. Members in PVM are seen as experts of their own experiences, while the researchers are facilitators of the inquiry process [1]. PVM also has the potential to go beyond facilitating discussions for needs assessments, to enable a platform for change. In this study it was important with such a platform giving voice to a minority groups individual experiences that otherwise would have risked never been heard. To protect confidentiality in this study, information that can identify

group members has been removed and replaced with pseudonyms. All members gave oral and written informed consent, and the Swedish Regional Ethics Board approved the study (ref: 2014/1577-31/2).

Participants

Participants in the photovoice group were asked to reconsider their role in the research project, as one of active group member in contrast to being a participant. We will therefore use the term member to refer to the people in the photovoice group.

Members were recruited using purposive sampling [16] through the Department of Endocrinology, Metabolism and Diabetes at Karolinska University Hospital. An endocrinologist working at the department identified persons to invite to the study through an ongoing self-management education program for persons with adrenal insufficiency during the period of September–December 2015. Invitations were extended to all persons with AAD who had participated in the self-management education ($n=15$) during this time, and who met the following inclusion criteria: having been diagnosed with primary adrenal insufficiency (Addison's disease), being over 18 years old, and being able to communicate in Swedish. The exclusion criteria were: having been diagnosed with adrenal insufficiency other than the primary kind, and having one or more concomitant conditions with severe physiological or psychological symptoms.

The persons who declined gave the reason that engaging in the study would be too time consuming for them, even though they found the study interesting. The endocrinologist contacted persons who agreed to receive further information by telephone for provision of this information as well as to affirm the inclusion criteria and ask for consent. These persons were also sent information by mail. Two women and three men ($n=5$) with AAD volunteered to join in the photovoice group (PVG). The group-members were between 40 and 77 years old, and had lived with AAD for 1–57 years. Three of them worked (50%, 75%, and 100% time, respectively), and two had retired. They were all from Sweden, and all but one had families including partners and children of different ages.

Data generation

The overall aim of the project was introduced to the Photovoice group (PVG) both in the initial invitation and during the first session. In this study, the

generation of data had three overall stages: identifying themes for weekly discussions, taking photos each week, selecting photographs, sharing and contextualizing stories, and identifying central issues and themes [17]. Each member of the group was engaged in making choices about the content for each of the subsequent sessions, the format for the PVG sessions, and the duration of time needed to fulfill the goals of the project. For instance, the group initially discussed the possibility of meeting for longer than 6 sessions (spread over several weeks); however, by the end of the sixth session the group decided that the goals for the group were accomplished, so no more sessions were added.

The first PVG session was an orientation session during which the researchers explained the aim of the study and the PVM. Consent was reconfirmed, and the group together decided on a set of ground rules. Ethical considerations regarding taking pictures and sharing information were also discussed within the group [1]. The group reached consensus in wanting weekly 2-hour sessions, with each member sending 3–5 photographs by email to the first author one day before each session. The first and last author facilitated the PVG sessions, which involved keeping track of time, logistics, and technicalities regarding the photographs as well as confirming the groups focus for each session. During the seven weeks, the facilitators encouraged the members of the PVG to co-facilitate the reflective sessions and the analysis. One of the facilitators was a senior researcher very familiar and skilled with the methodology and facilitation using photovoice. The other facilitator was a registered Occupational Therapist and a research-assistant with education and skills in facilitating group-activities and conducting qualitative interviews.

During the first session after the study was introduced, the PVG members introduced themselves. This led them into a discussion about barriers while living with AAD. The members thereafter decided that the theme of the subsequent week would be *experimenting with medications*, because the members' everyday lives revolved around their medicine intake. After the orientation session, each session started with a review of the previous week followed by a show and tell of the members' photographs. Each week the group together deciding what theme to focus on for the next session, such as *what makes me feel good, bad in everyday life*, and *planning and adaptations in everyday life*. In this way, the members of the PVG generated data both visually and verbally from individual and group reflections as well as joint discussions.

Throughout the PVG sessions, the members shared their points of view and collectively discussed and interpreted the photographs and emerging narratives. All sessions were carried out in an outpatient clinic where there were suitable facilities for group discussions. The sessions were audio-recorded, and the first author wrote reflective field notes after each session.

Data analysis

Data analysis was conducted in accordance with PVM [1,14] together with a thematic analysis [18]. The analysis started with the group-members organizing and analyzing the photographs and stories in two of the six PVG sessions. The first of these two sessions occurred halfway through the 7 weeks. All the photographs were printed, and the members discussed and clustered all photographs into groups with similar meanings. Based on the discussions, the group actively worked to identify themes, which contributed to visualization of common experiences. Serving as a way to facilitate discussions about what remained to be discussed in the last three sessions. In the final session, the members reviewed all the photographs and narratives generated during the process, and agreed on what to prioritize and what to do with the data generated. Results from PVM's are commonly presented as a photo exhibition, where a collection of photographs are displayed along with short narratives [1]. However, the members of the PVG wanted to capture and express their experiences in another way. The group's initial visual analysis of the photographic materials were therefore produced and presented as a booklet intended for others with AAD, relatives, healthcare professionals, and other stakeholders. The booklet included short captions and texts shedding light on the members' experiences of everyday life with AAD.

After the conclusion of the photovoice sessions, and in agreement with the group-members, the first and last author conducted a thematic analysis to identify and analyze patterns in the individuals' experiences [18]. The first author transcribed the recordings of all PVG sessions verbatim, and the analysis started with thoroughly reading all transcripts and field notes in order to become familiar with the data. Version 7.5.15 of the ATLAS.ti software package [19] was then utilized to reduce the raw information and to code, organize, and sort the data. Data linked to the aim of the study were assigned codenames, and then codes with similar meanings were merged and

preliminary themes were created [18]. The first and last authors then compared and integrated the themes from the thematic analysis and the PVG analysis. All members from the PVG also volunteered, at several occasions, to read and validate the final findings and gave comments that the authors incorporated to the final scientific presentation.

Throughout the data generation and analysis, the researchers used the Swedish language, while the synthesis of the quotes was translated into English. First, the researchers translated the quotations independently, and then the translations were compared for accuracy and adjusted to produce the final versions [20]. The thematic analysis of text material from the PVG sessions helped to illustrate themes with stories in combination with photos. Although no new themes were identified, the researchers see the analysis as strengthened by working both inductively and deductively. This allowed for a building on concepts and theories with an occupational perspective, to understand everyday life with AAD.

Findings

The researchers and the members of the PVG jointly concluded that the findings from this study were about managing everyday living with AAD. The members of the PVG described everyday life as more complex than they had gotten information about. It included facing barriers and negotiations, which often revolved around medicine management and different engagements in everyday life. The PVG members also had to advocate for themselves in different settings in healthcare, at work, and in home life, primarily because of the rarity of their disease. They had to become experts in an uncertain context, and find new pathways and solutions to make their lives work with a chronic condition. Five themes emerged from the analysis (1) Individual and fine tuning in everyday life, (2) It is not how it was, (3) The power of knowledge and support, (4) Becoming the expert in an uncertain context, and (5) Finding balance and paving new ways. Below we present the themes, illustrated by quotations and photographs from the PVG documentations.

Individual and fine tuning in everyday life

Everyday life with AAD was described as involving various symptoms despite the replacement therapies. The most prominent symptoms, which the members described, were physical and mental fatigue,

weariness, and nausea. Symptoms had to be regularly addressed through fine tuning of the person's individual medicine intake, activity- and stress levels. This was however challenging, since all the PVG members felt that the medication: '... seems not to be made for us patients' (Lisa). The group discussed and concluded that both the medication and the delivery of the medicine, several doses each day, was not optimal for either of them. Fine tuning in everyday life was also described as being very individual. David said that it was important to understand this, emphasizing that one cannot generalize with AAD:

It's so unbelievable that we all have the same journey, yet it's so different for everyone how life with Addison's works... Everyone seems to be completely different how they respond to the medicine and how they take their medicine. You can see patterns, but it's still different. What works for one does not work for others. It's important to get an understanding of this. That it's not possible to generalize around this disease.

The group-members differed in terms of how good they perceived their health and wellbeing to be, and what decreased their wellbeing. They all agreed that it was related to individual factors such as life situation, stress, and activity levels. Pointed out was also that because stressors were seen as individual, so were the required adjustments in everyday life. Lisa shared a story about her medicine management, portrayed in the photograph shown in Figure 1. She described it as a difficult balancing act, and something that she often had to engage her mind in:

I feel that it's difficult to balance the daily dosage. It sometimes feels like it isn't enough... One has to think about the dosage every day. One has to see how it feels, because if one doesn't then one will get sick and not feel good.

Another shared experience regarding fine tuning in everyday life was that the group-members perceived that they had to focus more on self-care than before their diagnosis, and also more than persons without AAD. They felt more unstable and frail than others did. Alice said:

I think one is more uneven in terms of energy as compared to others. Sometimes one feels more frail. It is also more often that one doesn't have energy now compared to before, before the diagnosis. There are more days one doesn't have energy, and to not have energy during the weekend after a whole work week is very likely.

Self-care and fine tuning were however seen as essential parts of everyday life in order to avoid the disease becoming worse or the risk of an adrenal

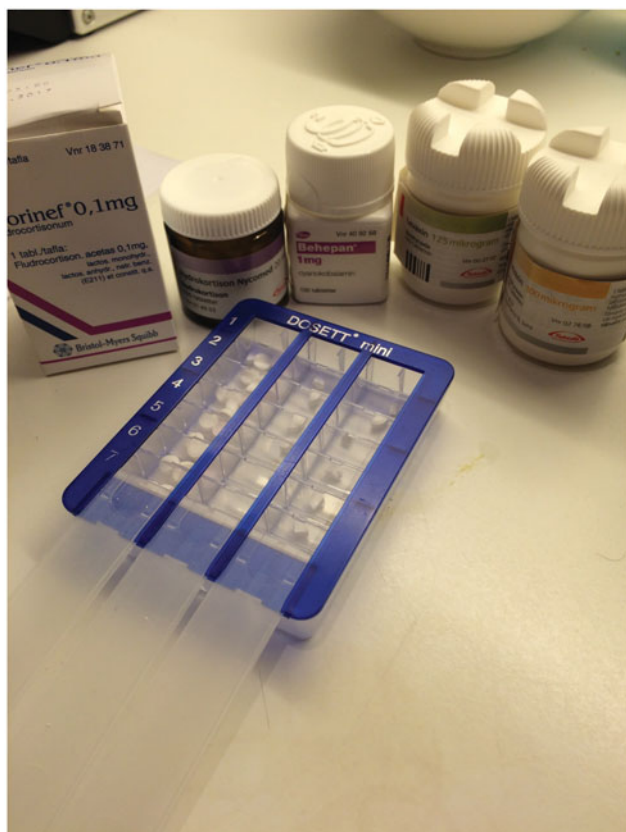


Figure 1. Fine tuning of the daily medicine management.

crisis. Besides experimenting with medications, fine tuning and self-care included taking enough time to rest, thinking preventively, being extra observant and cautious, and avoiding stress and infections to the greatest extent possible.

It is not how it was

One of the most common topics during the PVG discussions was the dual view of AAD and the information that existed about the disease and its impact on everyday life. There was a consensus in the group that healthcare professionals in different settings had repeatedly informed them that: 'Addison's disease is just a matter of taking some pills and everything will be alright.' This general picture of the disease did not match the members own lived experiences. Often during the PVG discussions, the members noted: 'That's not really how it is.' (Alice). On the contrary, the majority of the members described everyday life with AAD as complex, involving negotiations and feelings of insecurity regarding the everyday management of the disease. Several aspects could act as barriers to wellbeing, including increased sensitivity to stress and infections, reduced strength and energy, difficulty recovering after strain, and an increased need for rest



Figure 2. The dual view of the disease.

due to both physical and mental fatigue. There was also a shared experience related to the fact that the disease was an invisible one; it was a challenge to look healthy, tanned, and alert on the outside, while the inside told a different story. The photograph in Figure 2 represents the dual view of the disease in that everyday life with AAD was not always how it seemed to be from the outside looking in.

The group reflected together that the picture seemed to display a beautiful and harmonious day. However, Alice, who had taken the picture, said that even though the picture was beautiful it had several layers that might not be visible, much like the experience of their disease. Alice had taken the picture during a business trip abroad, which was demanding and stressful and decreased her wellbeing, which in turn required her to increase her medicine to cope. Therefore, although the picture might display a harmonious setting in the eyes of the beholder, Alice perceived it as the opposite of harmonious. This because of the extra sensitivity to stress that came with AAD. Another important layer in this picture for Alice was that these types of activities in daily life, whether they involved stress or not, were not something that her healthcare providers considered it fine to alter her medication for. This was very different from the actual lived experiences of the persons with the disease. It created stress for the majority of the group-members because they did not want to increase their dosage of medicine unnecessarily due to the potential negative consequences. The group-members

further perceived that they reacted to and were made unwell by a much wider range of influences than described by their healthcare providers. They also thought the recommendations regarding their medicine management were limited and difficult to implement. Although many recommendations were the same for all persons with AAD, the group argued that their needs were unique. Alice said:

It is different things that stress different people. For instance, information exists about taking extra (medicine) when visiting the dentist, but I don't feel stressed by going to the dentist. I get stressed and feel bad because of other things. I need to take extra (medicine) for totally other things.

The PVG members experienced that adjustments in everyday life and medicine management were vital for survival, in recovering from infections, a preventive method while undergoing procedures, and an essential part of self-care to enhance wellbeing in everyday life. However, the members' experiences did not match the information they had received from their healthcare providers.

The power of knowledge and support

An important aspect for wellbeing was having access to equal and adequate knowledge and information. However, the group-members said that the little knowledge and information that did exist was not always equal, adequate, or accessible to either them as persons with AAD or people in their surroundings. They argued that in order for them to make informed decisions they needed accurate knowledge about symptoms, medicine management, and everyday life. They also described how this knowledge could reduce their concerns regarding the disease in general. Carl said:

I also feel much better today now that I know, if I feel that I need, well then I take an extra pill. It doesn't matter. It's just good. It isn't something one knew before. It has become a big difference. One shouldn't be afraid of taking an extra one if it is needed. It is individual how one has to adjust the dosage.

The members of the PVG described that the lack of opportunity for self-management education and support regarding AAD was a big barrier in everyday life. They all expressed that they desired extended information and support, regardless of how long they had had the disease. They also agreed that information and support was especially important at the beginning, so one would know what to expect from



Figure 3. Photovoice analysis—sharing experiences with peers.

life with the disease. In order to learn more and get support, some of them had engaged with patient organizations; they said that sharing experiences with others in the same situation was helpful. They also expressed that although being a part of the PVG could sometimes be strenuous; it was worth it because being part of the group was valuable both for knowledge and for support. The photograph in [Figure 3](#) portrayed one of the PVG analysis sessions where the members pointed out that it was especially helpful to discuss issues of everyday life with one's peers. For example, David said: 'I think these meetings are really good. It's like therapy. My wife has noticed that I feel much better when I'm here. Don't stop! She says.' Lisa continued this thread, saying: 'One get something from giving to others. One has to go through all the phases. But perhaps it goes a lot faster when you have information and support along the way.'

The members also saw support from the healthcare system and their surroundings as a facilitator for their wellbeing. Being able to ask questions of experts and having people in their close environment who had knowledge about the disease were important to feel safe. However, at the same time, the members agreed



Figure 4. The building where David's dentist worked; a source of anxiety for him.

that because the disease was invisible they often felt poorly understood. Sometimes they even felt distrusted about their health and wellbeing, both when seeking healthcare and in working life. They even felt that being open about their disease could lead to their being overlooked for assignments and viewed as unreliable, and so they often chose not to tell anyone other than their immediate family about their illness. Alice said: 'That's why I don't tell. They don't understand. If I say something they just become distant.' In a similar way, and for the same reasons, the other group-members said that they had kept a low profile about their illness. Martin said: 'I've also actually done that throughout my entire working life. Some of the closest people you work with must know if one fall apart at work. But otherwise I didn't tell the colleagues I worked with.' The group further discussed how support and reasonable expectations from society and their surroundings did not always match their needs and capacities as persons with AAD. From their own perspective and opinions, this mainly had to do with the general lack of knowledge about what it was actually like to manage and live with AAD.

Becoming the expert in an uncertain context

Due to both the dual perception and the limited existing knowledge and support in healthcare and society,

a common view grew in the PVG discussions: people with AAD are forced to become their own experts. David used the photograph in [Figure 4](#) as a starting point to describe that even though it was challenging to interpret and act on the body's signals, he had no choice because there was insufficient information on how one should act with AAD. The picture showed the building where David's dentist worked, which represented anxiety for David. He had learned that even if this was not the case for everyone, in order for him to avoid becoming worse he had to take extra medicine before going to the dentist and avoid other stressors on that day. The PVG members also discussed the fact that because very few people had accurate knowledge about the disease, they were unable to rely on others for information and so had to be the ones with knowledge to find solutions in everyday life. David said: 'You have to be your own doctor.'

The majority of the knowledge the members of the PVG had learned about the disease was from their own lived experiences, and not from the standardized recommendations from healthcare providers. In addition, although all the members of the PVG had individually optimized medicine regimes, their everyday lives consisted of continuous individual assessments and negotiations, which included weighing information and knowledge against their symptoms and learning the skills they needed to cope. They

described this as difficult, but necessary because of the incomplete information and recommendations from healthcare providers. Carl for example shared that for a long time he had not known that he could not just go back to his regular dosage of medicine or activity level after a period of being unwell, without rapidly becoming unwell again. From his own lived experience, he had learned how important it was to ease himself gently back into everyday life. He said:

Once you have eaten extra (medicine), as you do when you feel bad for a period. Perhaps a double dose for a while, you can't just step down from one day to another. You have to take it slowly when you go down. Otherwise you get bad again.

The group further pointed out that it constantly occurred new situations, and that negotiations related to AAD continued regardless of how long the group-members had lived with the disease. Martin, who had lived with the disease for several decades, said that it took time to learn what you had to do. He also described that it was important to keep up with developments and be well informed and observant in order to make decisions. He said: 'One has to get to know one self. One shouldn't worry, but one has to be extra observant regarding symptoms.' The other members of the PVG agreed. They also said that because the disease was rare and in a context characterized by many questions, it was common to encounter healthcare professionals with less knowledge about the disease than their patients. In several parts of the healthcare system, the members of the PVG had experienced uneven and inadequate knowledge about the disease, particularly in contexts such as emergency care, primary care, and other specialist care. They had also experienced differences in endocrinology departments in various hospitals. These unequal encounters with healthcare professionals, without expertise in AAD, had often led to confusion, mixed messages, and even harmful situations. They described this as a large barrier, but it also became a reason for the members of the PVG to learn more themselves.

Finding balance and paving new ways

To find and maintain wellbeing, the PVG members needed balance in everyday life. Ways of finding balance were individual, but included new ways of living and adapting. Some of them had adapted by changing jobs or work assignments. Others had reduced their workload or working hours, in order to get enough time to recuperate. However, they all agreed that needs for adaptation were individual, and their



Figure 5. Abstaining from fun activities to find balance.

wellbeing mostly had to do with the amount of stress they perceived in their everyday lives and their ability to cope with stress. They also related wellbeing to the content of their work rather than their actual working hours. David said that everyone had to find something that worked for them:

I think one has to feel how the situation feels and find something that works for oneself. To find a good balance. To learn to cope with everything. A good work-life balance and a good medication. Then one feel good. There are many things that always have to match. Blood glucose, cortisol levels, how much rest one got earlier in the day. For me, the best time is after 4 pm on Saturdays.

Performing meaningful and engaging activities was an important way of finding and maintaining wellbeing. Martin noted that although everybody had their own preferences, these activities all had something in common; meaningful and engaging activities gave the group-members energy, recuperation, and a sense of being well rather than ill. It differed within the group how many of these and other activities they could engage in over a day or a week, and when it was the best time for activities to uphold wellbeing. However, they all agreed that it was vital to have time for recuperation between activities; otherwise, their wellbeing could rapidly decline. Another common adaptation for the PVG members was leading a calmer life than before the diagnosis. The photograph in Figure 5 portrayed Lisa's struggle to adapt in everyday life in the beginning with AAD.

Lisa shared a story about her favorite hobby, training and performing as a belly-dancer, which she was unable to continue with after she was diagnosed with AAD. In order to find and maintain balance, she had to scale down several activities in her daily life,

including belly-dancing, because self-care took so much time. The other members of the group agreed, saying that they no longer had the option of being involved in too many things. They often voluntarily abstained from both fun and fatiguing activities in order to maintain balance and wellbeing. David described that every week and day had a limit: 'One activity a day is enough.' Lisa also said that more rest was the key to finding balance. David continued saying:

I think with this disease and recovery... It takes much longer now than before one got the disease. One can keep going for a while, but then you have to take time to recharge your batteries. And maybe we're a bit like old batteries; we need to be charged a bit longer.

The members further described how they often made adaptations related to their disease in order to avoid using up all the energy needed to maintain their everyday self-care routines. Extended planning and sticking to routines regarding sleep, nutrition, and exercise were central to maintaining wellbeing. If their routines failed and their disease worsened, this could greatly disrupt their wellbeing and balance because their focus then had to shift to extended self-care. The group-members expressed that even if it was sometimes frustrating to make these adaptations in everyday life, planning and thinking preventively were important. This was a new way of life that could help them to stay in control and maintain balance and wellbeing. Martin said: 'I realize there's a lot of things that can affect it, stress included. To feel good one almost need to avoid stress entirely.'

Summary

The members of the PVG concluded that if they were to be experts in an uncertain context, they needed tools to be successful. They had all gone through self-management education for AAD, in which they learned more about the origins of AAD, adrenal crises and their medicine management. However, the members of the PVG described other aspects as equally important. For example, learning more about self-care and fine tuning in everyday life with AAD, individual symptoms, and medicine management, as well as knowledge about preventive actions such as: positive health behaviors, stress management, adaptations and coping in everyday life, and ways to find balance in and between activities in everyday life.

Discussion and study limitations

In this study, we used photovoice to gain insight into everyday life with AAD. Managing everyday life with AAD entails insecurity, mainly because of a lack of knowledge about how to support people living with rare diseases [2,3]. Moreover, people living with AAD often encounter healthcare providers who are not familiar with best practices in the area. To improve equity in health and quality of life, there is a need to develop and implement information, knowledge, and support related to AAD throughout the continuum of healthcare and society. In this context, accessibility needs in everyday life were experienced as a barrier for both persons with AAD and their significant others.

The members of the PVG further perceived everyday life with AAD as more complex than described in previous research and by their healthcare providers. In contrast to the perspective that rests on advances in medicine, the findings from this study portray that wellbeing among people with AAD is not always fully restored even after receiving replacement therapies, which is also supported in the literature [7–11,21]. The present study further highlights areas in everyday life that can be important for persons with AAD; avoiding too much stress, having enough time to recuperate, and ensuring balance in work and home life to promote wellbeing. This can perhaps be said to be true for many people, however, AAD can involve a rapid decline in wellbeing when stress or infections occur and when there is a need to deviate from self-determined life rules. Balance in everyday life is also described as disrupted because the focus often has to shift to self-care and accommodating one's symptoms. The PVG-members further described how the main barriers and facilitators in their everyday life lay within ordinary occupations. A distinct tension revealed itself between the members desire to engage in occupations and a simultaneous need to attend to the complex factors that determine successful self-management. This was portrayed in much the same way as was previously shown among young people with Type 1 Diabetes [22]. It is evident both from the present findings and from Pyatak's [22] study that the relationship between occupation and management of chronic conditions is affected by a range of complex factors. Occupations for the members in this study also seem to be able to simultaneously compromise health in one way, but can be powerfully health promoting in another way. This complicates our conceptualization of engagement in occupation as merely health promoting. It also provides an alternative

picture of how seemingly ordinary occupations such as work, social gatherings and physical activity can lead to health risks for some individuals when undertaken in combination with stress. This should challenge us to develop a more nuanced understanding of the relationship between engagement in occupation, health and wellbeing.

Improvements in treatment and recommendations regarding medicine management are needed for some people with AAD. This because the members in the present study described their existing treatment and recommendations as limited and inadequate. Extended patient education to promote wellbeing and reduce adrenal crises and other health risks in persons with different kinds of adrenal insufficiencies has also been suggested, however, existing implementations have shown uneven results [23–26]. This may indicate a need for additional approaches. Complements to existing preventive actions could include activities that are more practical, such as peer-based sharing and discussion of experiences regarding everyday life and management of the disease. Visual methods could also be utilized; using photos as a starting point for discussion. Interdisciplinary teams including professionals with expertise regarding activities in everyday life, such as occupational therapists, may also be needed to meet the needs of this group of persons.

The complexity of everyday life and how it significantly influences the PVG members' wellbeing when they participate in certain occupations was central in this study. In light of this, using occupational therapy frameworks, such as occupational balance, could have a potential role in current and future health care initiatives for people with AAD and other chronic conditions to promote health and wellbeing [27]. Existing treatment for AAD can be revised to incorporate knowledge about the disease in terms of individual and fine tuning of the medicine management, but also health promotive and preventive approaches such as: awareness of activity patterns, positive health behaviors, occupational balance, adaptations and coping in everyday life, and stress management. However, to enhance current practice, further research is needed. It is also important to discuss which aspects should be addressed by specialist healthcare and which should be carried out in primary healthcare settings or in other places in the community.

Previous research has shown that persons with rare diseases can experience great challenges in obtaining a timely and accurate diagnosis, as well as equal

access to healthcare and information [2,3]. Participatory methods and PVM in this context meant creating a forum for minority voices and emphasizing barriers in healthcare and in the community that are important for equity in health and quality of life for persons with AAD. PVM has also been suggested to be useful in understanding questions regarding the lived experiences of illnesses [4], and related to occupations and its negotiations in everyday life [1], and the present study has further strengthened its suitability for this. Additionally, PVM was helpful in identifying specific needs in relation to AAD, and hence may be a suitable supplement to other methods when focusing on client-centred approaches. The members of this PVG also expressed that participating and collaborating in the study and creating the photovoice booklet were both very valuable. They described how the sense of community they shared with each other when discussing the photographs made them feel supported. Prior to the PVG sessions, they had all attended self-management education for persons with AAD. However, being part of the PVG had helped them not only to feel empowered but also to learn things they had not previously known.

A challenge in PVM can be that the facilitators' and researchers' voices are too strong [1]. To counteract this, it is important to enable co-facilitation in the group. In the present case, the facilitators encouraged the members of the PVG to actively engage throughout the research process. The members were active from choosing their own themes for photography and discussion, to co-facilitating the PVG analysis, co-creating the PV booklet, and member-checking the thematic analysis. It can be argued that using the members photographs and stories to corroborate the consistency of the data and implementing triangulation through member-checking has enriched the findings of this study and can be positive from the perspective of credibility [28]. A limitation in the study however, can be that there were no external observers to independently code and validate the themes. However, the second author, who did not take part in the PVG-sessions was consulted regarding initial themes through discussions during the analytic process. In order to further engage in the process of reflexivity, regarding personal experiences and their impact while interpreting the results, the first author wrote reflective field notes after each session and discussed the results from the analysis with the research group [29].

The decision to conduct thematic analyses beyond the visual analysis performed together with the group can be challenged. However, the researchers in this project assert that the partnership in this PV project was strengthened by utilizing the groups strengths. The researchers had competencies in systematically exploring the data in another way than the whole group had. By working together, the group, including the researchers, were able to produce different types of presentations of the material, in an engaging and inclusive way. The participants were also given several opportunities, after the sessions had ended, to give feedback and comments on the findings from the thematic analysis. The comments were also incorporated in the final result.

Both sampling procedure and sample composition are important for trustworthiness in research [30]. Although this study's sample consisted of only five persons, the sample was seen as sufficient to enable group discussions in accordance with existing literature [1]. However, it should be noted that including more participants or a different group constellation might have given a different result. At the same time, it was important not to include too many participants because this could have limited the time available for each person to share, thus undermining the methodology. Another limitation that should be noted when interpreting the results is that the way the participants were approached meant that those who had not yet attended the self-management education for AAD were excluded. As were those who did not experience the disease as challenging and therefore chose not to be included. This may have affected the results of the study. It is not therefore possible to discuss whether other persons with either AAD or other kinds of adrenal insufficiencies would experience the same barriers and challenges in everyday life as this particular sample. However, the sample had a good variation in terms of age, gender, marital status, working ability, years with the disease, and level of illness perception, which adds to the transferability of these findings.

Seven weeks of engagement in PVG sessions initially appeared rather long to the group-members, but we established within the group that all sessions were needed. There was also a possibility to additional sessions if necessary. However, after seven weeks no new themes derived from discussions about everyday life and the members was satisfied with the amount of time spent in the PVG session. The PVG analysis was also coherent with the thematic analysis, but the thematic analysis provided more depth for the final themes.

Furthermore, the findings must be interpreted with the context of the study in mind, and careful judgment should be made in applying them to clinical settings. This study was conducted in central Sweden, where the context may differ from other settings in the same country or other countries. In addition, this study focused only on people with AAD. Given the differences in treatment approaches and demographics of people with other kinds of adrenal insufficiencies, this is an important area for future research. This study also only captured adults' experiences. In future research, it would be interesting to contrast these findings with views from younger persons with AAD, newly diagnosed persons with AAD, persons with different kinds of adrenal insufficiencies, and relatives, in order to enhance the picture of the impact that AAD and other kinds of adrenal insufficiencies can have on health, wellbeing, and everyday life. Finally, it would be interesting to use photovoice as a method in clinical practice. It could have a potential as a tool for discussions in self-management education programs, or in conversations with significant others and professionals in health care to bring awareness about AAD. It could also potentially be utilized as a tool in goal setting together with persons with the disease.

Conclusions

Everyday life with AAD is more complex than previous research has suggested and involves several barriers such as the medicine management, sensitivity to stress, and the lack of equal and adequate knowledge and support within society and the continuum of healthcare. Extended and validated information, support, and self-management education are needed to meet the needs of persons living with AAD. A complementary focus on everyday life in treatment was also emphasized as important. The use of participatory approaches and visual methods was successful in this context, showing the potential for further health research to enhance knowledge about how to design early health-promoting interventions in healthcare by engaging person's in the community. The methodology can also enable action for knowledge, as was evident from this study were a booklet including photographs and stories were produced, intended for others with AAD, relatives, healthcare professionals, and other stakeholders. Giving voice to a minority groups individual experiences of everyday life that otherwise would have risked to never being heard.

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References

- [1] Asaba E, Udman LRD, Mondaca M, et al. Visual methodologies: photovoice in focus. In Nayar S, Stanley M, editors. *Qualitative Research Methodologies for Occupational Science and Therapy*; 2015. New York. p. 232–257.
- [2] Forman J, Taruscio D, Llera VA, et al. The need for worldwide policy and action plans for rare diseases. *Acta Paediatr*. 2012;101:805.
- [3] Molster C, Urwin D, Di Pietro L, et al. Survey of healthcare experiences of Australian adults living with rare diseases. *Orphanet J Rare Dis*. 2016;11:30.
- [4] Lal S, Jarus T, Suto MJ. A scoping review of the photovoice method: implications for occupational therapy research. *Can J Occup Ther*. 2012;79:181–190.
- [5] Arlt W, Allolio B. Adrenal insufficiency. *Lancet*. 2003;361:1881–1893.
- [6] Husebye ES, Allolio B, Arlt W, et al. Consensus statement on the diagnosis, treatment and follow-up of patients with primary adrenal insufficiency. *J Intern Med*. 2014;275:104–115.
- [7] Burger-Stritt S, Pulzer A, Hahner S. Quality of life and life expectancy in patients with adrenal insufficiency: what is true and what is urban myth? *Front Horm Res*. 2016;46:171–183.
- [8] Bleicken B, Hahner S, Loeffler M, et al. Impaired subjective health status in chronic adrenal insufficiency: impact of different glucocorticoid replacement regimens. *Eur J Endocrinol*. 2008;159:811–817.
- [9] Forss M, Batcheller G, Skrtic S, et al. Current practice of glucocorticoid replacement therapy and patient-perceived health outcomes in adrenal insufficiency—a worldwide patient survey. *BMC Endocr Disord*. 2012;12:8.
- [10] Løvås K, Loge J-H, Husebye E-S. Subjective health status in Norwegian patients with Addison's disease. *Clin Endocrinol (Oxf)*. 2002;56:581–588.
- [11] Meyer G, Hackemann A, Penna-Martinez M, et al. What affects the quality of life in autoimmune Addison's disease? *Horm Metab Res*. 2013;45:92–95.
- [12] Bensing S, Hulting AL, Husebye ES, et al. Management of endocrine disease: epidemiology, quality of life and complications of primary adrenal insufficiency: a review. *Eur J Endocrinol*. 2016;175:R107–R116.
- [13] Wang C, Burris MA. Empowerment through photo novella: portraits of participation. *Health Educ Q*. 1994;21:171–186.
- [14] Wang C, Burris MA. Photovoice: concept, methodology, and use for participatory needs assessment. *Health Educ Behav*. 1997;24:369–387.
- [15] Asaba E, Wicks A. Occupational terminology. *J Occup Sci*. 2010;17:120–124.
- [16] Patton M. *Qualitative evaluation and research methods*. Beverly Hills: Sage; 1990. p. 169–186.
- [17] Berg B-L. *Qualitative research methods for the Social Sciences*. 5th ed. United Kingdom: Pearson's Educations Inc.; 2004. p. 195–208.
- [18] Polkinghorne DE. Narrative configuration in qualitative analysis. *Qual Stud Educ*. 1995;8:5–23.
- [19] ATLAS.ti. *Atlas.ti for Windows*. Version 7.5.15. Berlin, Germany: Scientific Software Development GmbH. 2015.
- [20] van Nes F, Abma T, Jonsson H, et al. Language differences in qualitative research: is meaning lost in translation? *Eur J Ageing*. 2010;7:313–316.
- [21] Bleicken B, Hahner S, Loeffler M, et al. Influence of hydrocortisone dosage scheme on health-related quality of life in patients with adrenal insufficiency. *Clin Endocrinol (Oxf)*. 2010;72:297–304.
- [22] Pyatak E. Participation in occupation and diabetes self-management in emerging adulthood. *Am J Occup Ther*. 2011;65:462–469.
- [23] Hahner S, Spinnler C, Fassnacht M, et al. High incidence of adrenal crisis in educated patients with chronic adrenal insufficiency: a prospective study. *J Clin Endocrinol Metab*. 2015;100:407–416.
- [24] Repping-Wuts HJ, Stikkelbroeck NM, Noordzij A, et al. A glucocorticoid education group meeting: an effective strategy for improving self-management to prevent adrenal crisis. *Eur J Endocrinol*. 2013;169:17–22.
- [25] Rushworth RL, Torpy DJ, Falhammar H. Adrenal crises: perspectives and research directions. *Endocrine*. 2017;55:336–345.
- [26] van der Meij NT, van Leeuwen RS, Vervoort SC, et al. Self-management support in patients with adrenal insufficiency. *Clin Endocrinol (Oxf)*. 2016;85:652–659.

- [27] Eklund M, Orban K, Argentzell E, et al. The linkage between patterns of daily occupations and occupational balance: applications within occupational science and occupational therapy practice. *Scand J Occup Ther.* 2017;24:41–56.
- [28] Maratos M, Huynh L, Tan J, et al. Picture this: exploring the lived experience of high-functioning stroke survivor using photovoice. *Qual Health Res.* 2016;26:1055–1066.
- [29] Carpenter C, Suto M. *Qualitative research for occupational and physical therapists: a practical guide.* Oxford (UK): Blackwell; 2008. p. 147–164.
- [30] Kuper A, Lingard L, Levinson W. Critically appraising qualitative research. *BMJ.* 2008;337:a1035.