Social consequences of disease-related symptoms in patients with metastatic small bowel NET: a qualitative study

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Abstract

Background: Neuroendocrine tumors (NET) are rare and often slowly progressive tumors. One of the most common localizations of NET in the gastro-intestinal system is the small bowel. It is known that disease-related symptoms, like flushes, dyspnea and diarrhea, can occur on a daily basis. These symptoms seem to influence the ability to perform daily-life tasks and fulfill social roles. But little is known about how patients experience and deal with these consequences in their day-to-day life.

Aim: To explore the social consequences of disease-related symptoms in patients with a metastatic neuroendocrine tumor in the small bowel.

Method: A qualitative study, according to the grounded theory approach was performed using semi-structured face-to-face interviews, between January and June 2018 in the Netherlands. Data were analyzed independently by two researchers using the constant comparison method. Data collection and data analysis alternated.

Results: Twelve respondents (male n=5, age range 42-66 years) participated. Fatigue, diarrhea and flushes were the most prominent disease-related symptoms. Fatigue was related with limitations in day-to-day life in almost all patients. In patients who experienced diarrhea and flushes, social activities were influenced by feelings of shame. Resilience seemed to be the decisive factor in the experienced social consequences. If patients are resilient, social consequences are less experienced as a burden. Over time, the patient perspective on their lives moved from being diagnosed with NET to living with NET.

Conclusion: All patients experienced some social consequences of disease-related symptoms. The experienced burden of these consequences seems to be determined by resilience.

Recommendations: Resilience seems to be an important factor in the experienced social consequences. Several instruments can measure resilience but further research is necessary to determine whether screening resilience in NET patients adds value compared to standard care.

Key words: neuro endocrine tumor, social consequences, resilience, qualitative research, grounded theory approach.

Samenvatting

Achtergrond: Neuro-endocrine tumoren (NET) zijn zeldzame en vaak langzaam progressieve tumoren. Een van de meest voorkomende locaties van een NET in het gastro-intestinale stelsel is de dunne darm. Ziekte gerelateerde symptomen die voorkomen zijn opvliegers, dyspnoe en diarree. Het is bekend dat deze symptomen zich dagelijks voor kunnen doen. Deze symptomen lijken van invloed te zijn op het uitvoeren van dagelijkse activiteiten en vervullen van sociale rollen. Desalniettemin is er weinig bekend over hoe patiënten de sociale consequenties ervaren.

Doel: Het exploreren van de sociale consequenties van ziekte gerelateerde symptomen bij patiënten met gemetastaseerde dunne darm NET.

Methode: Een kwalitatieve studie werd uitgevoerd door middel van semigestructureerde face-to-face interviews volgens de grounded theory approach, tussen januari en juni 2018 in Nederland. Data werden onafhankelijk geanalyseerd met de 'constant comparison'-methode door twee onderzoekers, waarbij gegevensverzameling en data-analyse werden afgewisseld.

Resultaten: Twaalf respondenten (mannen n=5, leeftijd variërend van 42-66 jaar) participeerden. Vermoeidheid, diarree en opvliegers waren de meest prominente ziekte gerelateerde symptomen. Bijna unaniem werd vermoeidheid ervaren als de meest beperkende factor in het dagelijks leven. Daarnaast werden sociale activiteiten beïnvloed door diarree en opvliegers indien deze symptomen aanwezig waren. Veerkracht lijkt een beïnvloedend factor in de ervaren sociale consequenties. Naarmate patienten veerkrachtiger zijn, ervaren zij de sociale consequenties als minder impactvol. Het perspectief van patienten verschuift naarmate de tijd verstrijkt van het krijgen van de diagnose NET naar het leven met NET.

Conclusie: Alle patiënten ondervinden enige sociale consequenties van de ziekte gerelateerde symptomen. De ervaren sociale consequenties lijken bepaald te worden door veerkracht.

Aanbevelingen: Veerkracht lijkt een belangrijke factor in de ervaren sociale consequenties. Verschillende instrumenten kunnen veerkracht meten maar verder onderzoek is nodig om te bepalen of dit een waardevolle aanvulling op de huidige zorg is.

Kernwoorden: neuro endocriene tumor, sociale consequenties, veerkracht, kwalitatief onderzoek, grounded theory approach.

Introduction

Neuroendocrine tumors (NET) are rare tumors that originate from neuroendocrine cells[1]. Irrespective of the localization, neuroendocrine tumors (NET) can be divided in functioning and non-functioning tumors. Functioning tumors are related to an overproduction of hormones such as serotonin[2] which can cause several symptoms. Non-functional NET are generally symptom free until the tumorload causes problems such as fatigue and pain due to an abdominal mass[3,4]. NETs are mainly found in the gastro-intestinal tract, the tumors of which are called gastroenteropancreatic neuroendocrine tumor (GEP-NET)[5,6]. The incidence for men and women was estimated at 2.4 per 100,000 in the Netherlands[1]. Surgical resection is the only potential curative treatment for a localized GEP-NET[7], but the majority of patients (58%)[8] receives a diagnosis in an advanced stage[9,10]. Slow progression is common, so the disease can be chronic for many years[1,11]. The five-year survival rate of metastatic GEP-NET is approximately 50%[1].

Previous research has shown that GEP-NET affects several domains of health and everyday functioning, such as physical, mental and social aspects[3,4]. Compared to the healthy population, patients with GEP-NET report a reduced health related quality of life[11,12]. A moderate negative impact of disease-related symptoms is experienced by 35% of the patients and a large negative impact by 39%[4]. Most cited physical symptoms are diarrhea, which is experienced by approximately 55% of the patients, fatigue by 61%, (abdominal) pain by 47%, hot flushes by 47% and dyspnea by 30%[4]. A lot of these symptoms occur on a daily basis, especially in patients with metastatic NET of the small bowel[8], one of the most common localizations of a GEP-NET[1,5]. Disease-related symptoms seem to influence social functioning in particular. This broad concept embraces all human relationships and activities[13] and involves the ability to perform daily life tasks and to fulfill social roles[14].

Disease-related symptoms result in limited possibilities to perform hobbies[3,4,9,15] and require lifestyle changes like decreasing physical acticivity[4]. Many patients report a negative effect on their work, only 22% of the patients say their work has not been affected by the disease[4]. Social and emotional distress can be caused by the above-mentioned physical symptoms, and can be increased by worries about the illness getting worse and the burden of the disease on family members[3].

To date, several survey studies are published about symptom burden related to GEP-NET. Results of these studies have shown a negative association between symptom burden and social functioning[4]. However, several studies show methodological shortcomings[16] and there is still a lack of in-depth knowledge. Small sample sizes (<50 patients)[3] and large groups of hundreds of patients, recruited from online sources and globally[4,8,12] might have introduced a recruitment bias[17]. Moreover, to our knowledge no published data is available about ‘how patients experience and deal with the consequences of GEP-NET related symptoms in their day-to-day life'. Therefore, we initiated a qualitative study in patients with metastatic small bowel NET to explore the social consequences patients' experience of disease-related symptoms.

Aim

To explore the social consequences of disease-related symptoms in patients with a metastatic neuroendocrine tumor in the small bowel.

Methods

Design and setting

Between January and June 2018, a qualitative study in a comprehensive cancer center in the Netherlands was conducted. The principles of a grounded theory approach were used because a general explanation how NET-patients define and experience these social consequences is not yet available. This method aims to move beyond description and to generate or discover a theory[18].

Population and domain

The study population consisted of patients with a functional, metastasized small bowel NET. Eligible patients met the in- and exclusion criteria: adult patients with a functional NET, a WHO performance status of ≤2[19], under 60 years old at the time of diagnosis, diagnosis made between 2009-2016. Patients with a severe primary psychiatric disorder (current depressive disorder or psychoses) were excluded. A purposeful sampling strategy with maximum variation was used to capture widely different experiences and to gain a broad understanding of the social consequences. Maximum variation sampling was used to create a variety in men and women of different ages and a varying time since diagnosis[20].

Data collection

With each participant, one semi-structured face-to-face interview was conducted by AG. AG is an experienced oncology nurse and health scientist in training. In preparation for the interviews, a pilot interview was held by AG to test the interview guide and to train her. This data was only used for training purposes.

Prior to the start of the study there was no relationship between the interviewer and the respondents. To create rapport[20] the interview started with an introduction in which the interviewer introduced herself and the study, withdrawing from the research was mentioned explicitly. The interview guide ascertained that all relevant themes were discussed[18,20] in a sequencing matching the process and response of the participants on the questions[20]. The discussed topics were 1. social functioning in daily life in general, 2. disease-specific problems and their influence on daily life, 3. role functioning on different levels (individual, partner, family, friends, colleagues and others), and 4. influence on or consequences of the disease on activities like household chores, work, hobbies etcetera. These topics were derived from literature[3,4,8,9,11,12,15] and expert knowledge. Interviews were audio-recorded and field notes were made directly after the interview[18]. The interviews lasted between 45 and 70 minutes (mean 54).

Procedures

The study team selected eligible patients on basis of information from the scientific administration of the hospital. Sixteen of the eligible 22 patients were asked to participate in the study. Five of them were contacted directly by phone based on permission of an informed consent from another study, eleven received a letter, and three of these eleven patients received a reminder after three weeks. All participants were informed about the study by telephone. In total, twelve respondents were included. Three failed to respond due to unknown reasons, one interview could not be planned due to differing calendars and travel distance. The interviews took place in the respondents' homes (n=5) or in the research department of the hospital (n=7). In two of the interviews, a partner was present.

Data analysis

Data were analyzed with the constant comparison method[18]. Data collection and analysis were alternated[21]. Interviews were transcribed verbatim with the audio recordings by AG. After reading and re-reading, coding of the anonymized transcripts was done on three levels. There were no themes identified in advance. The first step was open coding: all relevant information was coded[18]. Second was the axial coding, where relevant central phenomena and categories were determined[18,21]. After four interviews, the analysis shifted to axial coding. In the last stage the interrelationship of the categories was described and discussed with the study team[18]. A core component, which seemed to connect the different categories, emerged during these discussions. This core component helped to explain the social consequences patients experienced.

Two researchers (AG & JS) coded all interviews independently. After every three interviews, codes were compared until consensus was reached. During this iterative process codes were constantly revisited. Data analysis was supported by Nvivo Software[22] and memos were made during the analysis.

Data collection continued until data saturation was found in the data analysis. After this two more interviews were performed. Validity was enhanced by biweekly meetings for peer review with FdV and AB (supervisors). AB read and coded the first three interviews to see if the interviews were in line with the aim.

Ethical issues

The study was considered as a non-WMO research by the Medical Ethics Research Committee of the hospital, reference number P18NET. Data was handled according to the Dutch Personal Data Protection Act[23]. Informed Consent was obtained before the start of each interview and registered at the trial office of the hospital.

Results

In total, five men and seven women were interviewed. Mean age of participants was 58 years (range 42-66 years, SD 7.4). Baseline characteristics of the study population are presented in table 1. To protect identity, age is not presented in the table. Fatigue, diarrhea and flushes turned out to be the most prominent disease-related symptoms with social consequences in daily life. Some patients also experienced pain or weight loss. The text incudes Q references, which refer to specific quotes in table 2.

Social consequences of physical symptoms

Fatigue as limitation

Almost all participants experienced aspects of fatigue, with different consequences. Fatigue has a high impact on daily life and is felt as a limitation. Patients do need time to recover from activities, for example by fragmenting large chores in their household. Even if patients did not experience fatigue, patients still talked about careful activity-planning or taking rest to prevent exhaustion.

A lack of energy was the main reason if patients did not work or worked part time. Some patients felt so exhausted that even little things can feel as challenge, those patients are less able to enjoy social activities (Q1). Some of the patients experience a decreasing fitness in combination with fatigue. It means that patients cannot participate in exercise like before or are not able to do anything after work because of this feeling of exhaustion (Q2).

Some patients experienced a limited ability to sustain their concentration and a limited ability to manage competing demands, especially patients with a job. An important task or talking with others could work as a distractor and therefore postpone the fatigue. Secondly, having the opportunity to take half an hour of sleep during the day, could help prevent the feeling of sleepiness.

The most important coping strategy to deal with fatigue is careful use of energy, alternating activities and rest and adaptation of physical activities to better match the person’s abilities.

Diarrhea and feelings of shame

Diarrhea and flatulence can lead to feelings of shame and awkwardness in social situations. Increased toilet visits, especially in social situations like having dinner, are seen as inappropriate in society. This can induce feelings of shame in patients, especially if people do not know the reason for these frequent toilet visits. Whenever others were informed, patients experienced full support although feelings of awkwardness sometimes stayed (Q3).

The urge to go the toilet is recognizable for all patients who experienced diarrhea and was associated with a risk of fecal incontinence (Q4). When patients experienced diarrhea, activities like walking in the forest were avoided. Outdoor activities can give feelings of anxiety or stress and therefore have a negative effect on diarrhea. Some patients carried spare clothes and wipes with them, especially if patients have experienced fecal incontinence (Q5). Patients suffering from diarrhea were always aware of or focused on the presence of toilets. Patients do take this into account, sometimes even without noticing.

Flatulence, diarrhea and vomiting can be induced by spicy foods and oils. This means that patients carefully choose a dish when eating outdoors. Adapting their meal-choice was not felt as a big deal if this meant that the risk of those symptoms occurring could be avoided or reduced.

Flushes and feelings of awkwardness

Flushes were experienced by patients in different degrees. Almost all patients experienced flushes in the period before and directly after diagnosis. If patients experienced flushes, feelings and the adaption-pattern showed similarities with the symptom diarrhea. Patients experienced flushes after drinking alcohol, some experienced them after eating spicy food. Flushes occurring in front of people not aware of the disease could cause feelings of shame, it could elicit comments like ‘are you nervous?’ or the feeling that everyone was watching. For women it could be interpreted as a symptom of the menopause. But even then, patients often decided to not disclose the reason for those flushes for various reasons (explained in the paragraph about invisibility of NET). If flushes occurred in front of people knowing about the disease unpleasant reactions stayed out.

Social consequences of psychological and existential issues

Shifting perspective

Patients expressed that, over time, their perspective on live shifted. From a standstill and focus on having cancer, to moving forward and continuing with life (Q6 and Q7). This shifting perspective was expressed by almost all patients, irrespective of the year of diagnosis and the influence of the disease on their daily lives. This shifting perspective was followed by a contradiction in which patients mentioned the consequences of the disease on their daily lives were mentioned while also, in the same sentence, their lives or daily functioning was assessed as ‘good’ (Q8 and Q9).

Patients expressed that the time that is left should be used in a meaningful way. All patients asked themselves after the diagnosis or the period thereafter if their time was spent meaningful. Patients not able to work, often had voluntary jobs to contribute to the society. But it is not only about doing things like running a household or undertake social activities. It is about playing a role in the society that gives a feeling of fulfillment (Q10).

After diagnosis most participants tried to reintegrate, it was felt as a loss of self-esteem if patients did not succeed. Patients not able to work, struggled with the fact of being rejected for work. It takes time to find a way to cope with this.

Insecurity

Patients reported a double awareness. Although life goes on, the disease and its consequences are on the patients’ mind. Two types of insecurity were reported, insecurity in daily life and the fear of disease progression (Q11). When, for example, a new symptom appeared (*e.g.* pain or feeling more tired), patients’ associated this with their disease. Sometimes patients experienced that healthcare professionals did not take them seriously and sent them back and forth without solving the issue.

Patients reported more worries about their loved ones than about themselves (Q12). Patients told that their loved ones experience feelings of powerlessness to the situation. All patients expressed feelings of gratefulness to their partner who is a great support. Especially patients with children living at home expressed worries of leaving those children behind. Children also expressed feelings of anxiety to lose a parent (Q13). On the other hand, patients expressed that the advantage of their disease is that more time can be spent with their children. This gives a feeling of wealth.

To deal with these insecurities two coping mechanisms could be identified. One is the focus on living and enjoying life (Q14), which distracts from thinking about the end of life because this insecurity is unchangeable. The other coping mechanism is about seeing the disease in perspective and that it could be much worse (Q15). Besides these two coping mechanisms that were reported, a variety of other things may increase a sense of control. Examples are managing financial affairs, following mindfulness training, having a Fitbit, exercising or finding support in religion.

Invisibility of NET

Apart from the flushes, most patients did not show any apparent visible characteristics. This means on the one hand that patients are able to continue with their life like there is no NET, but on the other hand, patients have to stand up for themselves about physical limitations or if patients want to talk about their disease. Patients who struggled with this are confronted with incomprehension.

Apart from hospital visits, most patients did not feel the need to talk about their disease with others for several reasons: 1. the feeling that talking does not change anything and that there are more important things in life than the disease, 2. patients do not want be seen as a cancer patient and treated differently, and 3. patients do not want to burden their loved ones.

In the patient-partner relationships, humor was often a way of coping which helped patients to accept the disease.

Diagnosis 'NET' as a label

Several patients expressed that the diagnosis of having NET has a stigma in society. All patients experienced this with regards to major financial decisions or entering into insurance contracts (Q16). Some patients did not feel like being part of society (Q17). Those feelings were the strongest in patients who were not able to work.

Resilience

Various factors influenced the ability to adapt to the social consequences of the disease. These factors seem to be part of resilience, which seemed to play a central part in the social consequences of NET experienced by patients. See table 3 for an overview of the social consequences patients could experience of disease-related symptoms. Figure 1 shows the factors that have been addressed throughout this study. In patients where these factors of resilience were present, social consequences seemed to be less experienced as a burden. However, regardless of the social consequences, most patients in this study were able to adapt to their situation.

Discussion

This study explains how NET patients experience and deal with the social consequences of disease-related symptoms. The study revealed that fatigue, diarrhea and flushes are the most prominent disease-related symptoms with, varying, social consequences in daily life. Moreover, this study showed that many of these patients are able to adapt and cope with the disease. Over time, the perspective of patients changed from having cancer to living with cancer. Resilience seems to play a key role in the experienced social consequences and burden of the disease.

Several of the findings in this study were in line with other studies. Cancer-related fatigue (CRF) is known as one of the most common adverse effects of cancer[24–26]. In general, fatigue is associated with a lower quality of life and an influence on work, social and cognitive functioning[27]. Survey research about the experienced burden in patients with NET, shows a high impact on work due to the NET but leaves the reason for this unexplained[28]. The results in this study suggest that fatigue might be (one of) the key factor(s) for NET patients.

It is questionable if NET should better be compared with chronic diseases or with advanced cancers. From literature, three broad categories of adjustment are found for patients with chronic diseases, which seem to be applicable to NET patients: 1. adjustment is required across multiple life domains, 2. adjustment unfolds over time, and 3. marked heterogeneity in how individuals adjust to chronic illness[29]. Patients with NET show similarities with patients suffering from serious chronic diseases but at the same time are still cancer patients with an advanced disease associated with a high mortality rate[1].

For patients with chronic inflammatory bowel disease (IBD), physical symptoms like fatigue, diarrhea, pain and fecal incontinence are also common[30]. These symptoms can lead to stigmatization. A study that explored this stigma found that the stigma may be overcome through achieving emotional control, building strong networks, and developing mastery between life and disease[31]. This confirms that being open about your disease helps to deal with the consequences and helps to experience social support.

In contrast, a study about chronic headaches showed that making a disease visible can also lead to stigmatization[32]. Patients with chronic headache face a dilemma comparable to that of NET patients: conceal the disease or make it evident. Concealing the disease can lead to a lack of social support while making the chronic headache visible could result in stigmatization[32]. A major difference in this comparison is that NET is a cancer that can be in a chronic phase, but cancer itself is still associated with death by society[33,34].

All psychological and existential issues in this study were also found in other studies. For patients with IBD or advanced cancer the disease becomes a background normality[31,35,36], adjustment to reality is done by absorbing the illness into daily life[36,37]. This process is unique for every patient and affects the whole family[35,38,39]. Resilience is not explicitly mentioned in all these studies but themes like ‘keeping a positive attitude’ and ‘finding meaning in life’ were addressed[35]. These themes seem be in line with the concept resilience in our conceptual model.

In literature, resilience is described as a dynamic individual process of facing significant adversity or the adaptation to it[40,41]. Several definitions and a lack of consensus about the concept of resilience exist[42]. The interplay between individual, environmental systemic and biological factors is increasingly acknowledged[40,43]. Therefore, generalization of the conceptual model in this study to other populations should be done with caution.

Resilience is a complex concept that is yet to be fully understood; it would be too simple to explain resilience as a balance of protective and risk factors[44].

In this study, all patients experienced some social consequences, but patients seemed to be quite able to adapt to their lives. Apart from resilience, this might be the result of posttraumatic growth (PTG) which can occur due to the diagnosis of a life-threatening disease[45]. Resilience can be seen as an adaptive way of coping[40] while PTG can occur as a result of coping with traumatic events[45]. PTG can lead to negative effects but also to experienced positive changes in the following domains: relationship with others, perceptions of new possibilities, self-understanding, new dimensions of personal strength, spiritual changes and appreciation of life[45,46].

An important strength of this study was that data were analyzed independently by two researchers and discussed within the research team. Peer feedback was provided throughout the whole research process. Maximum variation in the sample was achieved in the following domains: years since diagnosis, employment status and level of education. However, a limitation of the study was that no theoretical sampling was done[18]. After saturation in data analysis, two more interviews were performed but the conceptual model was still in development and was not confirmed by new interviews. Another limitation is that, although all patients chose the location themselves, seven patients were interviewed in the hospital. The clinical environment of the research department may have influenced the interview. In addition, the results in this study may be too positive as only one patient in this study did not have a partner and it is known that social support is important[47].

For clinical practice it is important to realize that all patients living with a small bowel NET experience some social consequences and that resilience seems to be an important factor in dealing with them. There are several instruments that can measure resilience[41], but further research is needed to find out if screening resilience in NET patients adds additional value compared to standard care. Nursing studies of resilience in adults are still in their infancy[41]. More research on psychometric quality of instruments is necessary[41] before one can link consequences to the outcomes of the instruments and develop nursing interventions.

Conclusion

This study provided insight in the social consequences of disease-related symptoms as experienced by patients with a small bowel NET. All patients experienced some social consequences. Resilience seemed to play a key part in how much of a burden these social consequences were for the patients.

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Tables and figures

Table 1. Baseline characteristics of the study population (n=12)

ID	Sex	Marital status[a]	Level of education[b]	Employment status	Years since diagnosis	Current treatment
R01	M	M	Low	Retired	6	Somatostatin analogs
R02	F	M	High	Medically disabled	5	Somatostatin analogs
R03	F	M	Medium	Medically disabled	6	Somatostatin analogs
R04	M	M	High	Retired	8	Somatostatin analogs
R05	M	M	Medium	Full-time	8	Somatostatin analogs
R06	F	M	Low	Medically disabled	5	Somatostatin analogs
R07	M	M	Medium	Medically disabled and self-employed without staff	8	Chemotherapy
R08	M	M	High	Part-time	3	Somatostatin analogs
R09	F	M	Low	Part-time	6	Somatostatin analogs
R10	F	M	Medium	Medically disabled	9	Somatostatin analogs
R11	F	W	High	Retired	2	Somatostatin analogs
R12	F	M	Low	Not employed	2	Somatostatin analogs

Notes: [a]M: married, W: widow. [b] Low: primary school, lower secondary general, lower vocational; middle: higher secondary general education, intermediate vocational education; high: higher vocational education, university. [c] Years since diagnosis at time of interview

Table 2. Illustrative quotes of the (sub)themes

(Sub)themes	Quotes
Less able to enjoy activities	Q1: ‘Before, when the weather was nice, I would go and have a drink with friends. But now, after 2 hours, I have had enough – that's a shame.’ (R03)
Lack of energy	Q2: ‘The well-known complaint, I think with many people with cancer, and in my case that’s definitely true and something I experience on a daily basis, is that, uh, that energy, or the lack of energy, limits me in what I can do. That can be in sports, it can also be in social life, actually in everything. […] Well, I think you can say it is standard for me, that after the 15 hours that I work in the office – three times a week 5 hours – I always come home tired. And uh, then I know I should not be doing anything else anymore in the afternoon.’ (R08)
Shame and awkwardness	Q3: ‘If you go out for dinner, for example, then I get nervous and think: ‘ooh I hope it will all go well’, and often it does. But last night, for example, I had dinner with friends, and I had to go to the bathroom 4 times. And then I feel ashamed. […] But I just cannot stop it anymore, if I feel it coming, I just have to go. [...] but yes, in that case, you know you are with good friends but still, if their children would have been home, that would have already been a different story – I would not have gone to the bathroom, I would have gone home.’ (R03)
Urgency and shame	Q4: ‘In the beginning, the situation would be that when we went out, and I felt that I needed to go to the bathroom, the others would look at me as if they were saying ‘‘Again?’’. ‘‘Yes, sorry, again.’’ (R10)
Taking the illness into account in daily life	Q5: ‘My son […] he has to arrange an entire concert as a final exam. […] Then I think: ‘Oh dear, then I will have to eat something very light and I will not use that, uh, Metamucil for two days, because then, and then I will need something for, uh, well, incontinence material, so that I, eh, do not defecate everywhere. (Respondent laughs). But yes, I already think about that, like: ‘‘Oh dear, will it go well? Should I perhaps not go?’’, but that is not an option either, because then you are limited.’ (R03)
Shifting perspective	Q6: ‘I sometimes catch myself not thinking about it. That I have to realize [that I have the disease], actually you have to, because you are quite ill’. (R05) Q7: ‘[…] it does not always have to be on the foreground. […] because I say, there is more to life than this disease. And I've had this disease since 2009, so I've had it for quite a while now. In the beginning it was only about the cancer.’ (R10)
Contradiction of mentioning the disease and saying that they can do everything	Q8: ‘[…] 8 year later I am still here, it has only brought advantages, and of course I am ill, you know, I do not feel ill, the images just show you’ re very ill, but I do not feel that way, it sounds strange. But I can do everything, I can eat, I can run the stairs, I can ride my bike, […] I can do household chores, we can do activities, we go on holiday.’ (R07) Q9: To be honest, I have few complaints. Apart from that fatigue, but I mean I do not experience any pain, so everything goes on.’ (R06)
Feeling meaningful	Q10: ‘[…] before, we were both working. […] But, uh, now that is completely, now I think I am worth nothing anymore, like I am only the housekeeper, you know, that kind of thing, but I stay in touch with colleagues a lot, so I do a lot, I sing in a choir […]’. (R03)
Insecurity (future)	Q11: ‘Once I asked the nurse specialist: “What is my life expectancy?”, and she said, I believe: “Between 1 and 20 years”. I thought: ‘Oh well yes, what can I do with that.’ And then she said: “Yes after two years with those injections there is often, there can be a change. That you no longer respond to those injections.” I think the dosage can go up again. I can be very nervous about it, but let’s worry about that when we get there. What I can do is enjoy the fun things in life.’ (R11)

(Continued)

Table 2. *(Continued)*

(Sub)themes	Quotes
Consequences for loved ones are difficult	Q12: '[…] but yes there are things you cannot control, like the problem that is cancer, you have cancer, but the person you are with has a harder job. If you are ill, you are ill, you lie there. And the one that takes care of you is your partner. That is harder than, uh, being ill yourself, I am convinced of that. I don't have a problem with having cancer, we just continue, but the one who has to live beside you, sits next to you, that is much harder.' (R07) Q13: 'I had a period of a few months that I was really ill at home. They have seen and felt on a daily basis that it's not like: 'Daddy has the flu and will be in bed for a few days.' And as I said, we were open with them early on, as much as possible and as much as they could understand. So they certainly got that and they certainly felt the fear too. We also felt that they had the fear of losing their father, which is difficult.' (R08)
Living and enjoying life	Q14: 'I play music, my life is filled with all kinds of beautiful and important things, that's how I feel anyway, so then there is little time to worry.' (R04)
Seeing the disease in perspective	Q15: '[…] later you see disabled people in Africa and you think: 'It could always be worse.' […] and yes, now that I feel good again, I see those people and then I sometimes think: ''Their situation is worse.'' (R05)
Diagnosis 'NET' as a label	Q16: […] we wanted a new house, but that is not possible because you are ill, a mortgage, well, you just know, you won't get it. […] because then it is not given to you, you know, then you are a risk. (R07) Q17: 'It feels like you are no longer socially engaged or can work. That they can put you aside because you have that illness. And you are rejected for 80% and you can no longer be part of society.' (R01)

Table 3. Overview of social consequences of disease-related symptoms patients may experience

Social consequences of disease-related symptoms			
Physical symptoms	***Fatigue*** • Limited energy • Careful activity planning • Limited concentration and ability to manage competing demands • Decreasing fitness	***Diarrhea*** • Increased toilet visits • Focus on the availability of toilets • Risk of fecal incontinence • Avoiding certain food products	***Flushes*** • Feelings of shame • Avoiding certain food products
Psychological and existential issues	***Shifting perspective*** • Spending time meaningfully, wish to play a part in society ***Diagnosis 'NET' as a label*** • Financial consequences • Feeling of not being part of society	***Insecurity*** • Insecurity in daily life • Fear of progression • Worries about loved ones	***Invisibility of NET*** • Necessary for patients to stand up for themselves • No need to talk about the disease in daily life apart from during hospital visits

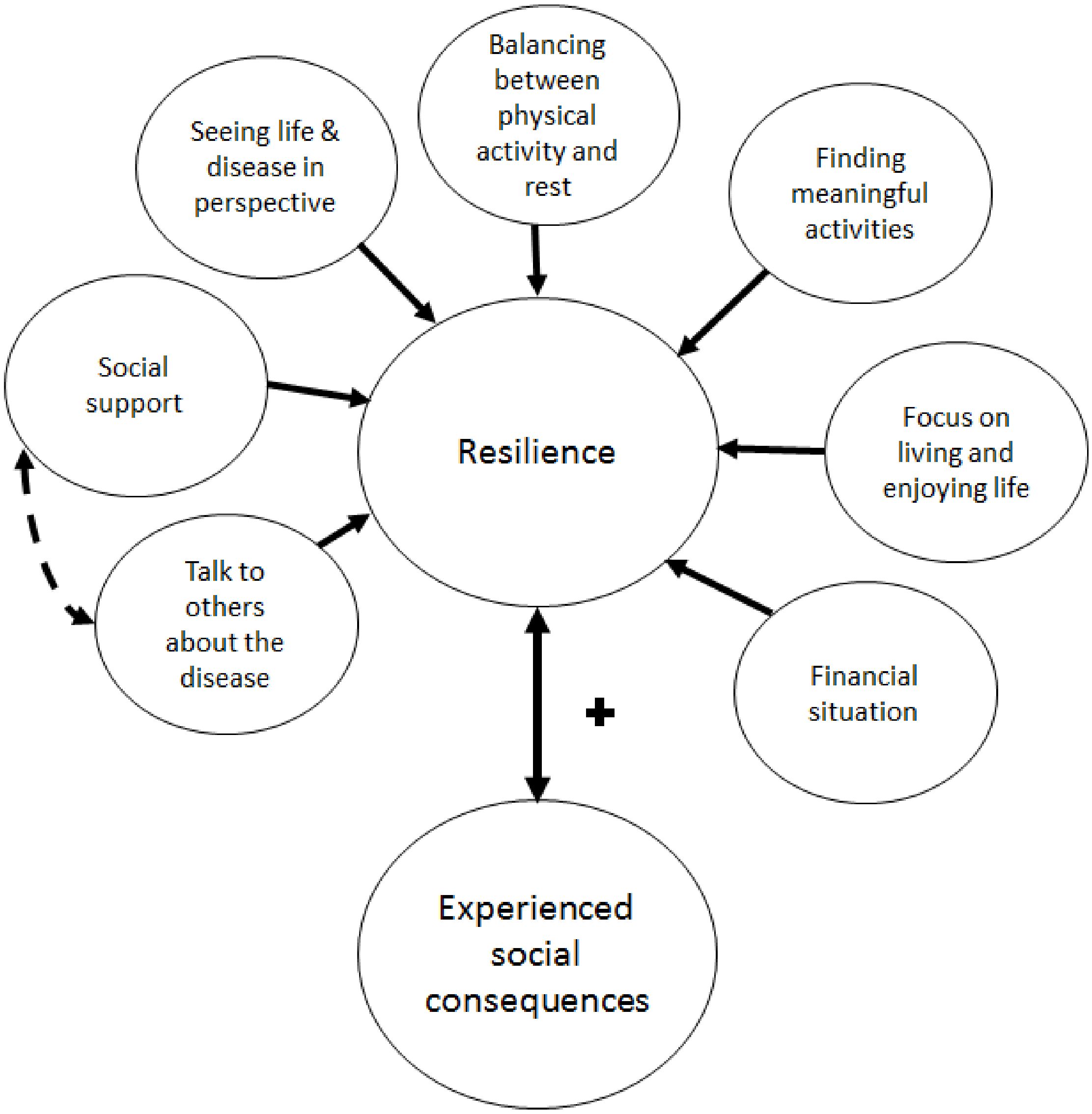

Figure 1. Factors with a positive influence on resilience and experienced social consequences