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A qualitative study
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Daily living and rehabilitation needs in patients and caregivers affected by Myeloproliferative Neoplasms (MPN): a qualitative study

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**Authorship**
All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by HKR, MK and KBD. The first draft of the manuscript was written by HKR and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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**Conflicts of Interest**
The authors report no conflicts of interest, and no benefits to be disclosed. The authors alone are responsible for the content and writing of the paper.
Daily living and rehabilitation needs in patients and caregivers affected by Myeloproliferative Neoplasms (MPN): a qualitative study

Abstract:

Aims and objectives: To explore experiences of daily living and identify rehabilitation needs in patients and caregivers living with myeloproliferative neoplasms.

Background: Myeloproliferative neoplasms are chronic haematological cancers. Studies report a high symptom-burden but little is known about supportive care and rehabilitation for this patient group.

Methods: 48 patients and seven caregivers attending a 5-day rehabilitation course were interviewed in 12 focus groups. Systematic Text Condensation was used to analyse the interviews. Reporting adhered to COREQ.

Results: Two main themes for patients were found: The loss of choice and identity due to the need to prioritize energy and The schism of being a person but also a patient. Patients described how living with myeloproliferative neoplasms meant having to prioritize energy and, therefore, losing freedom to choose activities. This changed their identity and impaired their quality of life. Patients of working-age seemed to struggle the most in balancing the disease, family, social relationships and work. One main theme was found for caregivers: Influence of the disease. Caregivers reported how the disease limited their social lives, that the disease brought psychological strain, extra work, and that communication between couples was impaired. When both patients and caregivers participated in rehabilitation courses, they reported better understanding between couples and more open
conversations. Rehabilitation needs identified were mainly in relation to psychosocial support and patient education, although needs varied across patients and caregivers.

**Conclusions:** Patients and caregivers expressed difficulties in adjusting to the lives the disease enforced upon them. Our findings indicate that myeloproliferative neoplasms patients and their caregivers would benefit from a combined model of psychosocial support, patient education, peer support, and rehabilitation interventions based on an individual needs assessment.

**Relevance to clinical practice:** Nurses can be responsible for individual needs assessments and refer patients and caregivers to suitable supportive care and rehabilitation interventions.

**Keywords:** MPN, myeloproliferative neoplasms, supportive care, rehabilitation, symptom burden, quality of life, fatigue, daily living, psychosocial support

**Introduction**

The Philadelphia-negative myeloproliferative neoplasms (MPN) are a group of heterogeneous cancers in the bone marrow characterized by clonal excess hematopoiesis (Hultcrantz et al., 2020; Mesa, Jamieson, et al., 2016). MPNs include myelofibrosis (MF), polycythemia vera (PV), essential thrombocytthemia (ET), and MPN-unclassifiable (Mesa, Jamieson, et al., 2016). MPNs are rare with an age-standardized incidence is 4.45/100,000 person-years for all MPNs (Hultcrantz et al., 2020). The protein tyrosine kinase JAK2 is mutated in more than 90% of patients with PV and approximately 60% of patients with ET or MF (Barbui et al., 2011). Since the discovery of the mutations that activate the JAK pathway, the diagnosis and management of patients with MPNs has evolved (Mesa, Jamieson, et al., 2016). However, for patients suffering from MPN a cure is not possible (Spivak, 2017; Tefferi & Pardanani, 2015). Despite this, the life expectancy for most MPN patients is often favourable compared to most malignancies (Tefferi et al., 2014). Current conventional treatment guidelines mainly focus on preventing thrombohaemorrhagic events and treatment strategies include, for example, phlebotomy, aspirin, and cytoreduction (Barbui et al., 2011). Even so, studies have shown that despite treatment, a high symptom burden persists (Johansson et al., 2012; Mesa et al., 2003). Studies report a high level of fatigue in the majority of MPN patients and symptoms like pruritus, night sweats, and bone pain are frequently reported (Brochmann et al., 2020; Mesa et al., 2007). These symptoms and especially fatigue are identified as a major contributor to poor quality of life (QoL) for patients with MPN (Mesa, Miller, et al., 2016; Scherber et al., 2016). Hence, the need to ensure they receive rehabilitation and supportive care with a focus on improving function and QoL post-diagnosis. Rehabilitation for cancer patients, in general, encompasses exercise-based and

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interdisciplinary rehabilitation interventions (Stout et al., 2016), in which nurses play an important role in assessing patients’ needs (de Leeuw & Larsson, 2013). However, as the nature of different cancer types varies, the rehabilitation needs may also vary depending on the patient group.

Studies on patients with MPN have, so far, primarily focussed on treatment regimens for MPN patients (Mesa, Jamieson, et al., 2016; Mesa et al., 2017; Spivak, 2017; Vannucchi et al., 2015), while only a few have addressed how to provide rehabilitation interventions (Brochmann et al., 2019; Pedersen et al., 2018; Tolstrup Larsen et al., 2018). Pedersen et al. (2018) published, to our knowledge, the first ever intervention study on effectiveness of exercise-based rehabilitation in MPN patients. The study showed increased physical capacity but found no effect on fatigue or QoL. Until now, to the best of our knowledge, no qualitative studies have explored daily living and the corresponding rehabilitation needs of MPN patients. Understanding the rehabilitation needs of MPN patients is essential before developing and testing further rehabilitation interventions (Craig et al., 2008).

The purpose of this study was to explore the experiences of daily living of MPN patients and caregivers, and their corresponding rehabilitation needs by:

1. Gathering knowledge on the everyday living challenges of patients and caregivers affected by MPN
2. Exploring patients and caregivers self-reported needs and preferences for rehabilitation

**Methods**

**Design**

This study has a qualitative design with a phenomenological approach aiming to understand the participants lived experiences (Malterud, 2012). Focus group interviews were utilised for data gleaning and Systematic Text Condensation (STC) for analyses. The STC method is a descriptive and explorative method for thematic cross-case analysis of qualitative data, and represents a pragmatic approach (Malterud, 2012). Although inspired by phenomenological ideas, various theoretical frameworks can be applied (Malterud, 2012). In our study, we chose the biopsychosocial framework of rehabilitation (Engel, 1977; Wade & Halligan, 2017), which constitutes the theoretical basis for the rehabilitation courses during which the focus groups were held.

**Participants and setting**

Participants were recruited nationally to residential rehabilitation courses from nine different Danish haematological departments. The departments referred patients to the rehabilitation courses using
a specific referral questionnaire completed by their treating physician. Inclusion criteria for the rehabilitation courses were age ≥18 years, a MPN diagnosis (including MPN-unclassified), able to be present at the course all five days, and a self-reported score of 4 or over (on a 0-9 linear analogue scale) indicating how close they are to living the life they desire (Kristensen, 2005; Pedersen et al., 2018). Participants for the focus groups interviews in this study were recruited from the rehabilitation course; hence, the inclusion criteria were the same. One of the three rehabilitation courses included caregivers. Caregivers were recruited for focus groups in the same manner as the patients.

All participants on the rehabilitation course took part in the focus group interviews except one who declined to participate on the grounds of the focus groups being audio recorded. In total, 12 focus groups were carried out, 10 with patients (N=47) and two with caregivers (N=7).

The setting for the focus groups was a research clinic that provides residential rehabilitation courses for patients with serious, chronic illnesses (Rasmussen et al., 2020). The rehabilitation courses consist of five days of interdisciplinary rehabilitation comprising of: physical exercise, patient education, psychosocial support, and dietary counselling. In addition, they have an explorative aim to collect evidence for rehabilitation for a variety of patient groups (Rasmussen et al., 2020). A detailed description of the course, including a week-plan, has been published previously (Pedersen et al., 2018). During April to June 2016, two courses of residential rehabilitation were held for MPN patients only and one was for MPN patients and their caregivers. The focus group interviews reported in this study were held at the beginning of the course, when patients had gained a certain amount of trust between each other but had not yet been subject to the rehabilitation intervention. The interviews were carried out in an informal sitting room with couches and pleasant lighting commonly used for informal group sessions held during the courses. Aside from participants, the moderator and an observer, no one else was present during the focus group interviews.

Fifty-six percent of patients (n=27) and five of the seven caregivers were female. The mean age of patients was 62 years (35-82) and the mean age of caregivers was 69 years (62-81). Demographic data on participants are presented in Table 1.

Research team and reflexivity

The role of moderator for the focus group interviews shifted between the first and second author (both female) with the addition of a male rehabilitation coordinator acting as an observer. The second author was an experienced qualitative researcher and nurse, qualified at PhD level, working with the patient group as a research leader in a collaborating hospital. The first author, qualified at
MSc level, had no previous experience with the patient group and was employed as a research assistant.

During the preparations for the rehabilitation courses, staff, including the moderators, were given a one-hour lecture about MPN pathology. This made us aware that the patient group may potentially suffer from a high symptom-burden.

The moderators took no other part in the residential rehabilitation course other than to conduct the focus group interviews. The observer acted as a rehabilitation coordinator for each of the three courses, and therefore, had interaction with the participants beforehand. The focus group interviews were carried out on the second day of the five-day residential rehabilitation course, leaving the rehabilitation coordinator little time to form relationships with the interviewees. Opening the interviews, the moderator and observer offered some background information about themselves; for example, age, education, experience, residence, and family status; afterwards asking the respondents to disclose the same information to achieve an open atmosphere.

**Data collection**

Focus groups were chosen for data collection as they are suitable for explorative studies and can produce an enrichment of data, exploiting group dynamics with participants commenting and elaborating on each others’ accounts (Freeman, 2006; Halkier, 2010). Focus groups were semi-structured with an interview guide developed by the researcher group (Table 2). The interview guide was not pilot tested before the focus group interviews were conducted.

All interviews were audio recorded and afterwards transcribed by the second author and a secretary. Field notes were made by the moderators during the focus groups interviews. Each interview lasted 1.05-1.20 hours (h.mm), resulting in approximately 16 hours of recordings. During each residential-course, a cluster of four independent focus group interviews were conducted with three to six patients or caregivers – 12 focus groups in total. The size of the focus group depended on the number of participants on each course. Thus, data saturation and repeat interviews were not discussed. Transcripts were not returned to participants for comments but response validation was conducted during interviews by posing clarifying questions (Elo & Kyngas, 2008).

**Analysis**

The first and the second author independently coded the data. The analysis focused on the width of the field by describing the content of themes and views identified in the interviews. Themes were derived by following the steps provided in the STC procedure: 1) total impression – from chaos to themes 2) identifying and sorting meaning units – from themes to codes 3) condensation – from
code to meaning 4) synthesizing – from condensation to descriptions and concepts (Malterud, 2012). Figure 1 provides a graphic presentation of the process: code identification and their synthesis into concepts. Following the analysis, findings were framed through the themes of the interview guide using a biopsychosocial framework (Engel, 1977; Wade & Halligan, 2017) to identify derived needs of the patients and caregivers within the four core areas of rehabilitation: physical, psychological, social, and existential (WHO, 2003).

NVivo 12 programming was utilised for analysis and Consolidated criteria for reporting qualitative studies (COREQ) served as a guideline for reporting the study (Tong, Sainsbury, & Craig, 2007) (See Supplementary File 1).

**Ethical considerations**

Verbal and written informed consent was obtained and participants were informed about the aim of the focus groups, that anonymity would be preserved, and that participation in the focus group was voluntary and participants could, at any time, withdraw from participating in the interview. The study was approved by the Danish Data Protection agency (J.nr. 2008-58-0035).

Given that the focus group interviews were held at the beginning of the residential course, any rehabilitation needs that surfaced during the interviews were followed up and met, if possible, during the week. Participants did not have the opportunity to provide feedback on the findings.

**Results**

**Main themes**

For patients, all coded nodes in NVivo were eventually collapsed into two main themes: “The loss of choice and identity due to the need to prioritize energy”; and “The schism of being a person but also as a patient”. For caregivers, all coded nodes were collapsed into one main theme: “Influence of the disease” with two subthemes: “Influence on social life” and “Communication in the relationship” (Figure 2). Based on patients’ and caregivers’ expressions of needs and derived from topics touched upon in the main themes, an overarching theme “Supportive care and Rehabilitation needs” was constructed (Figure 3). This theme comprised of needs from both patients and caregivers, and is unfolded at the end of this section.

**Patients**

**The loss of choice and identity due to the need to prioritize energy**
Generally, the patients expressed that the MPN disease had put a stop to the active and interesting life they lived before the symptoms of MPN had occurred. Many described their body as the thing that prevented them from doing what they would like to, and that their body was something to be hauled with them in their activities. Some explained that they would like to travel but the disease meant they needed permission from their treating physician and risked falling ill during a trip, which resulted in them refraining from travelling. Others expressed how they refused to let the disease determine or limit them in their activities. They proceeded to pursue the desired activity, subsequently facing a fatigue so severe that they would be incapacitated for a time. Our data included several stories about how the disease and the effect it had on the body limited their freedom of choice.

*It is hard to accept that you have no control over the trajectory [of the disease] and that you cannot decide for yourself how your life should be – it is terrifying not to be able to negotiate with the disease, because you can with many other things.* (Female patient, FG #7)

One of the most prominent themes about living with MPN was the effect the symptom burden had on the patient’s identity, in terms of both self- and social identity. From having had one self-image to, after the onset of the specific symptoms, becoming someone who the individual could not identify with was a major cause for suffering among the patients who had more severe symptoms. The fatigue and lower level of energy especially frustrated the majority of the patients who felt that they could no longer be the person they used to be – in both their private and professional lives. Having a ‘thick head’ was touched upon by some of the patients who expressed this as a feeling of not being able to think clearly, which also affected their ability to work. One male patient even explained how he used to be the go-to person at work when colleagues needed advice but how this was no longer the case.

*The thing about memory, I have noticed that I have always been the person people would ask for advice at work, but now, people don’t ask me anymore – it’s certainly, decidedly degrading and touches upon all of one’s identity.* (Male patient, FG #2)

Although some of the patients knew that they would have to accept the situation and find new hobbies, the loss of identity left others with passing depressive feelings and a sense of lower self-worth.
I don’t even know who I am - I was once superwoman who could do it all but now I cannot even be there for my children or carry out my work and we are struggling financially. I don’t know what’s going to happen to us at home, even though my husband is fighting for us. I need to find a new identity and that’s the hardest part. (Female patient, FG #3)

Due to the lower levels of energy the majority of the MPN patients experienced, they needed to prioritise between activities based on what was important to them and what was necessary. Some described how there were only a certain amount of energy and that whatever they chose to spend it on would result in them ‘lying fallow’ for days afterward. Resting periods had become essential for the severely burdened. A female patient described how she viewed her former life (prior to MPN) to be a flow of activities whereas her present life was compartmentalised into isolated tasks followed by resting periods. Cutting down on, for example, social activities, had resulted in an impaired quality of life for the majority of the patients. However, cutting down on activities was necessary in order to leave energy for the truly important things, for example, those that yielded the most value for the individual.

I've cut down on a lot of my social activity for the benefit of work and family – I'm sad about it, but I just don’t have the energy for a social life anymore. (Male patient, FG #9)

I prioritise having my grandchildren staying over – but then it also takes three days before I’m back on top. (Female patient, FG #9)

The schism of being a person but also a patient

This theme comprises the patients’ constant struggle with identity, wanting others to show consideration, and at the same time wanting to be viewed as an equally valuable person.

Patients described different levels of symptom burdens. A few patients did not feel encumbered by their disease at all, while most felt that the symptoms limited their lives from a lesser to a larger extent. Ultimately, across the data, it seemed that patients dealt with their symptoms differently depending on their level of symptom burden and the point that they were at in their life. The younger patients and those with younger children often struggled more with their symptoms than did the older patients. The most common and debilitating symptom was fatigue, with pruritus and difficulty concentrating/thinking taking a second place, but also commonly mentioned were psychological issues.
The fatigue really impacts your quality of life – you cannot do what you want to, physically, mentally or socially. (Female patient, FG #7)

Patients expressed frustration about the lack of understanding of their situation from the people surrounding them and struggled with symptoms limiting their ability to participate in activities (social, household, etc.). Many patients had had unclear symptoms for years without being taken seriously by either their caregivers or physicians. For some, this had been a struggle and a cause for self-doubt as they were dismissed as being lazy, crazy and/or hypochondriacs. For these patients the diagnosis came as a relief. Still, many felt that those surrounding them downplayed the severity of symptoms and had begun questioning themselves as a result. They wanted others to acknowledge that they were ill without being viewed as completely incapable.

They [the friends when the patient cancelled plans] will say: ‘Don’t you draw that “sickness card” again!’ (Male patient, FG #3)

...What can you really say to get people to respect the fact that you’re ill, without already being buried? (Male patient, FG #9)

Being a person with a chronic disease meant spending a lot of time and energy on medical consultations. For patients already suffering from fatigue too many consultations would take its toll. Patients described how they would need to be proactive in order to coordinate check-ups so that they would not have to go to the hospital, for example, for two consecutive days with the extra transport time this involved.

I am amazed that there is so little streamlining on patient consultations. Why can’t they be flexible on where and when to get checks and blood tests, and why can’t they coordinate hospital checks instead of spreading them out over several days? As a patient, you have to be proactive and nudge to change your times, or coordinate them, and ask if it can be in a hospital near one’s residence instead, etc. (Female patient, FG #5)

Caregivers

Seven caregivers participated in the focus groups. Across these, there were great variations in the sense of burden. Caregivers were mostly retired and all were older than 60 years of age. None had children living at home. This made their accounts free of some of the strains that the younger patients described; however, some caregivers talked of how their partner’s disease restricted the life they had hoped to live in the aftermath of their working life.
Influence of the disease

The disease impacted caregivers’ daily lives in several ways related to managing time and psychological impact, the latter being more serious.

Similar to the patients’ accounts, caregivers talked about how much time was spent on travelling to and attending medical appointments. Caregivers’ expressed that these appointments would naturally control their everyday lives, as they had to fit other activities around the appointments. Moreover, due to their partners’ fatigue, caregivers had to manage more tasks around the house and in the garden, which also took time away from other activities.

The psychological impact was mostly centred on worry. Before the partners’ diagnosis, caregivers told of long periods with worry and thoughts about the future.

> When I’m thinking about last year, he was... (...) I found it quite terrible to see up close how he was doing. He didn’t have the energy for anything, he was down and just wanted to be allowed to have peace and there I thought to myself: are we going to go through a longer period of this? I just couldn’t... It was hard.
> (Female caregiver, FG #2_Caregivers)

After the diagnosis, caregivers expressed how they paid extra attention to their partners’ condition and worried if a symptom flared up, for example, a fever which would have to be checked at the hospital.

> Well I feel great, it’s not like that, but I always pay attention when we’re at home or out golfing, like I wonder how she’s doing. She’s laughing and seems happy, well then I’ll have to trust that she’s fine, but still... (Male caregiver, FG #1_Caregivers)

Meaning for social life

Having had a long life with work and responsibilities, many caregivers had had dreams of a joyous retirement with time to travel, spend time with friends, and take up hobbies. However, due to their partner’s disease, and the symptoms it came with, these dreams were harder to realize. Caregivers told of how fatigue was especially a restrictor for engaging in social activities, when it, for example, meant that the partner needed to leave an event early to rest. Even though this had an obvious impact on the patient’s life, the caregivers’ quality of life was also impaired by such restriction. One caregiver expressed how she did not view herself as old enough to sit in a chair all day and added...
that she sometimes felt guilty because she, as opposed to her partner, had the energy and inclination to be socially and physically active.

Sometimes I feel guilty. I mean, I am capable and active. I cannot stand sitting, (...) I have too much energy. ...but sometimes I think to myself, should we change our whole [life just because of that disease] ... right? So many things can go through your head like that. (Female caregiver, FG #2_Caregivers)

This issue was raised by female caregivers. Neither of the two male caregivers expressed the same frustrations.

Communication in the relationship

Caregivers reported communicative frustrations associated with difficulties talking about matters related to the disease, for example, the impact it had on the caregiver or their joint lives. They expressed how starting a conversation like this could be misinterpreted as a lack of consideration for the patient and end up unintentionally hurting the patients’ feelings. Sometimes, caregivers would just want to know how their partner was doing when they expressed reluctance to talk about the disease all the time. Thus, communication in the relationship would largely be on the patients’ terms.

Well I get to air my frustrations sometimes [about not getting to talk about the disease] but then again I don’t want it to be like our entire day is ruined. I’m getting the sense that she will now go around wondering about ‘why hasn’t he done this’, ‘why hasn’t he asked me about that’, if you know what I mean? I don’t want... She won’t say: ‘don’t ask me about this or don’t worry about that’. I find it hard. (Male caregiver, FG #1_Caregivers)

Supportive Care and Rehabilitation needs

This section includes topics of importance to patients and caregivers, based on stated and extrapolated needs. The latter refers to the authors’ interpretation of rehabilitation needs corresponding to expressed challenges.

Based on patients’ expressions of challenges with former and new identities, in addition to explicit remarks, support to cope with the psychosocial challenges associated with the disease was one of the most prominent rehabilitation needs. Patients expressed the need to have quality in their lives on many occasions during the interviews. Psychosocial support was needed in relation to coping with increased morbidity and death, and especially with the struggle of fatigue and the effects it had

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on different aspects, for example: occupational, and thereby financial; social; and existential. The need for support to facilitate conversations of a serious nature within families was apparent. Patients made explicit requests for consultations with psychologists and social workers.

*No one talks about the uncertainty about the future, and we have so many questions of an existential nature, which would be good to talk to other professionals about – for example a social worker.* (Female patient, FG #7)

Many patients had found the patient education provided during the residential rehabilitation course useful as this information resonated with their own experiences. This included the information about the disease in general that was provided. Moreover, the inclusion of caregivers during these sessions made caregivers more aware of symptoms and symptom-management, which ultimately led to a better understanding and open conversations between spouses.

*...If one is away [on the course] and the other one is home (...). I don’t know... You will not be able to discuss things the same way... One could say something and the other person could respond: “oh well really, when did that become a problem? Is that something you learned when you were away?” Therefore, I think it is a very, very good thing [to participate as a couple].* (Female patient, FG #5)

In addition to the explicit comments about difficulty obtaining information about MPN diseases, this points to a need for patient education for patients and their caregivers. Aside from patient education, peer support also proved useful. Many patients and caregivers found it rewarding to meet likeminded MPN patients and share experiences with them.

*I wanted to come and meet peers, right, to see how and for how long they’ve had MPN, how they live and things like that, because I have to adapt my everyday life too... so I get here... and there are only positive accounts – “I’ve had it for 10 years” and such. What a relief, right?* (Male patient, FG #6)

Aside from the above mentioned needs, other requests were made for physical exercise support and sexologist advice. As needs varied across participants, a thorough needs assessment is called for.

**Discussion**

**Summary of findings**

Patients were affected by MPNs mainly in loss of their freedom to choose activities, and a changed identity, regarding both self- and social identity. Moreover, patients reported a lack of understanding from those surrounding them. The disease and the symptoms it entailed had an
effect on the patients’ ability to participate in activities in their private, working, and social lives. Caregivers felt this effect too, although from a slightly different perspective. They experienced the secondary effects in that their private and social lives were restricted, too. Besides this, caregivers reported psychological strains due to worries, extra house chores, and impaired communication between couples. When participating in the rehabilitation courses together, patients and caregivers reported benefits in terms of better understanding and more open conversations. We found that patients and caregivers would benefit from psychosocial support and patient education and that a needs assessment should form the basis for identifying which rehabilitation interventions patients and their families need in order to maintain a good QoL.

Discussion of results

Our data analysis suggests that one of the major impacts of the disease among MPN patients is the effect the symptoms have on their identity, both self- and social. As touched upon in the introduction, MPNs are cancers from which patients are not cured but rather MPNs have a chronic nature. Looking through literature on the chronically ill, the issue of identity is not unique to MPN patients. Charmaz (1983) gleaned qualitative data across 57 chronically ill people with various chronic diseases in Northern America. Charmaz found that the loss of self was a fundamental form of suffering as the chronically ill person observed their former self-image crumble away without simultaneously developing an equally valued new one (Charmaz, 1983). Charmaz’ findings underline the main finding of our study, namely that patients suffering from MPNs have trouble coming to terms with the fact that they have lost their former identity and now have to form a new one, which they do not value as much. This was highlighted, for example, by the quote by the female patient, stating that she was once superwoman capable of everything but now struggles with the most basic things.

Moreover, Charmaz states that people surrounding the chronically ill person generally view them through a framework of acute care with the assumption that an illness causes temporary disruptions of self instead of the continuing loss of self, experienced by patients (Charmaz, 1983). Our finding that patients generally felt left without understanding and consideration from those surrounding them supports this statement. While caregivers and social networks might show consideration and perhaps even worry when symptoms are acute, this consideration and worry seems to have a time limit. Thus, some patients in our focus groups expressed how they had trouble being taken seriously because their symptoms had been unclear for years and made them seem more lazy than ill. Adding to the struggle with identity this lack of consideration was hard on patients. In addition, the restrictions of living with a chronic illness is corroborated by Charmaz’ findings: “Their illnesses
become the focus of their lives as treatment regimes, periods of discomfort, medical appointments and the problematics of mundane activities structure and fill their days.” (Charmaz, 1983, p. 172). In the context of our findings, patients as well as their caregivers, addressed how the time spent on the disease was a major energy and time expenditure. This was especially true for patients who to begin with needed to structure their days in order to prioritize energy where it was needed most. Thus, time spent on the disease robs time and energy from things that could increase their QoL.

The MPN patients included in the present study have many things in common with other chronically ill patients. Unsurprisingly, we found that younger MPN patients were the most challenged subgroup due to the high demands placed on them at the current stage in their life. This finding is confirmed by other studies (Kochovska et al., 2018; Mor et al., 1994). Further, our interviews indicate that the younger MPN patients especially struggle to live up to the expectations of those surrounding them as well as their own regarding socialization. That younger patients struggle to meet expectations of those surrounding them is something that studies before ours have found and discussed (Charmaz, 1983; Mor et al., 1994). Indeed, patients with living-at-home children described spending most of their energy on taking care of their children and family, thus leaving little energy to spend on socializing with friends, as shown in previous studies of MPN patients (Mesa, Miller, et al., 2016).

Our study aimed to explore needs and preferences for rehabilitation, drawing on the biopsychosocial model of illness (Engel, 1977; Wade & Halligan, 2017). According to the biopsychosocial model of illness, an array of components are of importance for the patient, ranging from personal context, over physical context and impairment, to temporal context (Wade & Halligan, 2017). In order to help patients handle their symptoms and cope with their changed lives, it is necessary to identify their individual, complex problems (Handberg, Thorne, & Maribo, 2018). In our study population, we identified psychosocial support and patient education as the most significant rehabilitation interventions needed by patients and caregivers, who expressed a need for information about the disease and in general needed support to cope with psychosocial issues related to the disease. Some also expressed a need for other types of interventions, such as physical exercise and sexologist advice. Cross-disciplinary support, for example, from rehabilitation nurses, psychologists, social workers, and physiotherapists, could help address many of the challenges our participants experienced and help them learn to cope with their changed lives individually and as couples (see Figure 3) (Gerber et al., 2017). This holistic rehabilitation approach is supported in an array of studies. Physical exercise has been shown to be beneficial in other haematological cancer populations (Bergenthal et al., 2014; Eckert et al., 2017). Besides exercise, and supported by our findings, other activities should be of psycho-educative nature, including patient education or support groups, in which nurses have a key role (Armes et al., 2009; de Leeuw & Larsson, 2013;
Hansen et al., 2013). A recent study found that caregivers express higher needs for information than patients (Rood et al., 2017) underlining the need to incorporate caregivers in rehabilitation psycho-education. In our study, patients expressed the usefulness of caregivers being present during education, and caregivers expressed that the rehabilitation course instigated couples to open up and have painful conversations. This is in line with studies showing that a family communication pattern where discussions of the cancer experience are avoided has negative consequences; whereas open communication in families can help patients cope and overcome challenges of cancer survivorship (Badr & Taylor, 2006; Lepore & Revenson, 2007; Mallinger, Griggs, & Shields, 2006).

Thus, reducing distress and discomfort associated with diseases such as MPNs calls for a holistic approach taking into account all aspects of a patient’s life, including their caregivers (Engel, 1977; Wade & Halligan, 2017). It is important to note, however, that because MPNs may progress (Tefferi et al., 2014) supportive care and rehabilitation interventions should focus on improving QoL, rather than trying to return patients to a former state of functioning (WHO, 2003).

Strengths and limitations

During the focus groups, it became apparent that patients would mirror themselves in their fellow patients, in turn, influencing positively on their understanding and acceptance of their MPN disease. Being allowed to talk openly with peers in a confidential setting, appeared to have a therapeutic effect, an effect also found in another study of 17 men with various cancers (Adamsen et al., 2009).

To our knowledge, there has not previously been published a qualitative study exploring MPN patients’ and their caregivers’ life situation and self-reported needs for rehabilitation interventions, although this provides an essential basis for the development of a suitable rehabilitation intervention (Craig et al., 2008). A major strength of our study is that it provides valuable information to clinicians about how to support MPN patients and their caregivers. Furthermore, the number of included patients is high given the small population of this rare disease. Even so, the study has a number of limitations.

The awareness of the high symptom-burden of many MPN patients obtained through the lecture prior to the residential courses might have caused interviews to be affected by our prior knowledge that QoL in all MPN patients was poor. However, this prior knowledge was rebutted during the interviews by some patients’ presentation of a content life, lived with very little effect from the disease. MPN patients expressed different views of life with MPN despite the information stated in the pre course lecture.
Only twice did the subject of sexual functioning come up during interviews. It is highly unlikely that the two patients raising this topic were the only ones having problems in this area. It could be argued that taboo subjects would surface more rarely due to the focus groups occurring early in the course, and also more rarely than it would during individual interviews, which is a potential limitation of our study. Choosing focus groups is at the cost of each participant’s chance to describe their experiences in-depth (Kvale, 2008), an issue we addressed by keeping the focus groups small and consciously activating all participants.

Because patients were referred to the residential rehabilitation courses via their consulting physicians and because the courses involved being away for five days overnight it would be plausible to suggest that selection bias is present in our study. However, it is reasonable to consider that needs present in the investigated population would also be present, and perhaps more pronounced, in a slightly less resourceful population.

Furthermore, due to the small number of caregivers, conclusions based on their narratives should be interpreted with caution.

While our study has many strengths: benefits of peer support, novelty of research, and a high number of patient participants with this rare disease; a number of limitations might have affected the findings and should be considered in the interpretation of them. These include: our prior knowledge of the symptom-burden, possible difficulty raising intimate subjects in a group setting, selection bias due to sampling method, and the small number of caregivers.

**Compliance with ethical standards**

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Conclusion**

The present qualitative study openly explored daily living amongst patients with MPN and their caregivers and explored corresponding needs for rehabilitation. We found that the majority of MPN patients and their caregivers had difficulties adjusting to the lives the disease forced upon them, leading to impaired QoL. Our findings indicate that MPN patients and their caregivers would benefit from psychosocial support, which include the family’s needs and focus on coping with the changed life circumstances. An individual needs assessment provided by nurse practitioners will be essential.

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in order to identify other needed rehabilitation interventions. Because MPNs may progress, improving QoL should be the main focus of supportive care and rehabilitation interventions.

**Relevance to clinical practice**

Ultimately, the goal will be to develop clinical guidelines on how to provide supportive care and rehabilitation to this specific population, identify the setting in which to provide these, and prioritise implementation of this evidence-based knowledge. Before this is accomplished, it is essential that nurses in clinical practice focus on assessing patients’ and caregivers’ needs in order to refer patients to suitable supportive care and rehabilitation interventions. Future studies should focus on clarifying the timing, content, components and provision of rehabilitation services to MPN patients and caregivers.

**BOX:**

What does this paper contribute to the wider global clinical community?

- Patients with MPN have to prioritize energy and therefore lose freedom to choose activities. This changes their identity and impairs their quality of life. Patients of working age seem to struggle the most in balancing the disease, family, social relations and work.
- Caregivers to patients with MPN report how the disease limits their social lives, that the disease brings psychological strain, extra work, and that communication between couples is impaired.
- MPN patients and their caregivers need support to cope with their changed lives. Nurses can utilize needs assessment and refer patients and caregivers to suitable supportive care and rehabilitation interventions.

**References**


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Rasmussen, A., Jespersen, E., Backmann, T. B., & Jarlbæk, L. (2020). *Praksisbeskrivelser - Forskningsklinik REHPA. Standard rehabiliteringsforløb for mennesker med eller efter kræft [Practice Descriptions - Research Clinic REHPA. Standard Rehabilitation Courses for People with or after Cancer]*. Nyborg, Denmark:


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with hematological malignancies and their informal caregivers: Not "one-size-fits-all".

*Psycho-Oncology, 26*(12), 2040-2047. doi:10.1002/pon.4414


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Figure 1: Coding tree: identified codes and their synthesis into themes

**PATIENTS**
- Limitations of the disease
- Identity
- Prioritizing energy
- Symptom coping
- Lack of understanding from those surrounding the patient
- Time-consuming disease

**CAREGIVERS**
- Time-consuming disease
- Worrying
- Limitations on social life
- Communication in the relationship

**THEMES**
- The loss of choice and identity due to the need to prioritize energy
- The schism of being a person but also a patient
- Influence of the disease
  - Meaning for social life
  - Communication in the relationship

Figure 2. Illustration of main and subthemes of the analyses. The circular arrows are intended to illustrate how themes are interrelated.
Figure 3. The figure depicts how the themes relate to rehabilitation needs and subsequent supportive care and rehabilitation interventions.
Main themes

*Patients*
- The loss of choice and identity due to the need to prioritize energy
- The schism of being a person but also a patient

*Caregivers*
- Influence of the disease

Expressed and extrapolated rehabilitation needs

**PATIENTS**
- Identity
- Symptom coping
- Prioritizing energy
- Social life
- Communication

**BOTH**
- Social life
- Communication

**CAREGIVERS**
- Social life
- Communication

Rehabilitation interventions

*Cross-disciplinary rehabilitation approach based on needs, e.g.*
- Patient education (nurses, doctors, peers)
- Psycho-social support (nurses, psychologists, social workers, sexologists)
- Physical training (physiotherapists, occupational therapists)
Table 1. Semi-structured interview guide for the focus groups

<table>
<thead>
<tr>
<th>Main topics</th>
<th>Example of concrete questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Briefing and introduction</td>
<td>Information, informed consent</td>
</tr>
<tr>
<td>Generally on the disease</td>
<td>How do you experience living with MPN?</td>
</tr>
<tr>
<td>Physical level</td>
<td>Which physical challenges do you experience?</td>
</tr>
<tr>
<td>Psychological level</td>
<td>Which mental challenges do you experience? Anxiety? Other reactions?</td>
</tr>
<tr>
<td>Social level</td>
<td>Which changes in your social life has the diagnosis brought about? Work life? Family life? Social network? Leisure time?</td>
</tr>
<tr>
<td>Existential / spiritual level</td>
<td>Which thoughts about life and death has living with MPN cause you to have?</td>
</tr>
<tr>
<td>Rehabilitation needs</td>
<td>What do you need that health professionals can provide?</td>
</tr>
<tr>
<td>Debriefing</td>
<td>How did you find the experience of participating in the interview?</td>
</tr>
</tbody>
</table>

Table 2. Residential rehabilitation stay participant demographic data

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th>Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants, n ( % )</td>
<td>48 (100)</td>
<td>7 (100)</td>
</tr>
<tr>
<td>Women, n ( % )</td>
<td>27 (56.3)</td>
<td>5 (71.4)</td>
</tr>
<tr>
<td>Age, mean, years (range)</td>
<td>61.8 (35-82)</td>
<td>69.3 (62-81)</td>
</tr>
<tr>
<td>Educational attainment, n ( % )</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>n (%)</td>
<td></td>
</tr>
<tr>
<td>------------------------</td>
<td>------------------</td>
<td>----------</td>
</tr>
<tr>
<td>Basic school (&lt;11 y)</td>
<td>8 (16.7)</td>
<td>6 (85.7)</td>
</tr>
<tr>
<td>Upper secondary/vocational school (15-17 y)</td>
<td>20 (41.7)</td>
<td>1 (14.3)</td>
</tr>
<tr>
<td>Higher education (&gt;17-18 y)</td>
<td>12 (25.0)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Missing</td>
<td>8 (16.7)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td><strong>Working, yes, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>24 (50.0)</td>
<td>6 (85.7)</td>
</tr>
<tr>
<td>Sick leave</td>
<td>5 (10.4)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Part time job</td>
<td>1 (2.1)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>1 (2.1)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td><em><em>Co-habitation status</em> n (%)</em>*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living alone</td>
<td>7 (14.6)</td>
<td></td>
</tr>
<tr>
<td>Living alone, but in a relationship</td>
<td>3 (6.3)</td>
<td>†</td>
</tr>
<tr>
<td>Living with partner</td>
<td>38 (79.2)</td>
<td></td>
</tr>
<tr>
<td>Living with children</td>
<td>7 (14.6)</td>
<td></td>
</tr>
<tr>
<td><strong>MPN-subtype, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Essential thrombocytosis (ET)</td>
<td>12 (25.0)</td>
<td></td>
</tr>
<tr>
<td>Polycythemia vera (PV)</td>
<td>19 (39.6)</td>
<td>†</td>
</tr>
<tr>
<td>Myelofibrosis (MF)</td>
<td>15 (31.3)</td>
<td></td>
</tr>
<tr>
<td>MPN-unclassified</td>
<td>2 (4.2)</td>
<td></td>
</tr>
<tr>
<td><strong>Duration of disease, years, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;5</td>
<td>25 (52.1)</td>
<td></td>
</tr>
<tr>
<td>6-10</td>
<td>11 (22.9)</td>
<td>†</td>
</tr>
<tr>
<td>11-15</td>
<td>6 (12.5)</td>
<td></td>
</tr>
<tr>
<td>&gt;16</td>
<td>4 (8.3)</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>2 (4.2)</td>
<td></td>
</tr>
</tbody>
</table>
* Checking more than one box was possible
† Data not available for caregivers