Supporting work participation of people with a chronic disease

Vooijs, I.M.

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CHAPTER 3
Value of work for employees with a chronic disease

Vooijs M, Leensen MCJ, Hoving JL, Wind H, Frings-Dresen MHW

Abstract

**Background:** Most people with a chronic disease value participation in work. Knowledge is limited, however, as to what extent employees with a chronic disease value participating in work, and for which main reasons. Also limited research is available on which specific aspects contribute to the perceived value of work.

**Aims:** To evaluate for which main reasons, and the extent that employees with a chronic disease value participation in work, and which aspects motivate or demotivate employees in work.

**Methods:** A survey of members of three large patient federations was performed. Respondents had a chronic disease and were of working age. The extent and reasons for valuing work were analysed using descriptive statistics, (de)motivating aspects were qualitatively analysed using MAXQDA.

**Results:** The 1683 respondents valued work on average at an 8 on a scale from 1 to 10 (1: ‘work is not at all important to me’ and 10: ‘work is extremely important to me’). Most frequent reported reasons for valuing work were the provision of income, social contact, and the ability to contribute to society. Motivational aspects in work were being financially independent, having positive social contact with colleagues or clients, and having the ability to contribute to society. In contrast, negative social contact, performing useless work, and having little autonomy demotivated people.

**Conclusion:** Employed people with a chronic disease generally value work, mainly because it makes them financially independent, provides social contact and enables them to contribute to society.
Introduction

On average, 28% of people of working age have been diagnosed with a chronic disease [1] that negatively affects their ability to participate in work [2,3] through impaired functioning [4,5]. Those with a chronic disease are more frequently unemployed and work fewer hours than the general population [2,3]. Nevertheless, previous research indicates that people with a chronic disease see participation in work as an important rehabilitation goal [4,6]. In addition, work has been shown to benefit health [7], which underlines the need for people with a chronic disease to participate in work.

Previous research has reported various reasons for valuing work; work is not only seen as a source of income, but can also provide social contacts [8] and a sense of belonging and self-worth to an individual [9]. People with a chronic disease also describe work as indicative of ‘returning to normality’ [6,10,11], a signal that one is getting better [10] or that everyday life has been restored [12]. Despite this research, the extent to which workers with a chronic disease value their work, and the main reasons they do so, is unclear.

In addition, participation of people with a chronic disease in work is influenced by numerous factors, such as motivation, job satisfaction, feelings about one’s current work [13] and the fit of the job to the individual [14]. In order to provide further insight into specific factors that contribute to a perceived value to work, this study explored factors that are motivational for workers in their work or vice versa.

The concept of a perceived value of work has also gained recent attention [15], with authors arguing that when the needs of employees are met in the workplace, people are more likely to be capable of and willing to continue participating in work. These needs could be fulfilled by having reasons to value work and experiencing motivational aspects in work. Insight into the reasons for valuing work and motivational aspects could support organisations and occupational health professionals (OHPs) to stimulate those aspects that motivate and enable people in work, and counteract those factors that demotivate and therefore hinder people in work.

This study therefore explores the value of work, and in particular:
1. To what extent do employees with a chronic disease value their work?
2. For which main reasons do employees with a chronic disease value their work?
3. Which aspects in work motivate or demotivate employees with a chronic disease?
Methods
This cross-sectional study consists of an analysis performed on data derived from a questionnaire, which was distributed among members of three large patients federations (leder(lIn), the ‘Patiëntenfederatie Nederland’ and the LPGGZ) in the Netherlands. These patient federations are coordinating organisations, in which a number of smaller associations are affiliated, each focusing on a chronic disease, such as heart disease, rheumatoid arthritis, cancer, lung disease, diabetes, chronic obstructive pulmonary disease (COPD), etc. The members of these organisations are people who have been diagnosed with a chronic disease or multiple chronic diseases for a significant period of time. Members were invited to complete an online questionnaire by email. In addition, social media was used to recruit participants. Respondents were included in the analysis when they were employed and had a self-reported chronic disease. Only those respondents who answered all the questions related to our research were included in the study.

Demographic data were collected on gender, age, education level, and type of employment contract. With regard to value of work, respondents were asked to indicate how important work was for them and were asked about the reasons they valued work (see Table 1). These categories were based on earlier research on why work participation is important, focusing on people with specific chronic diseases [10,15,16]. With regard to aspects in work motivating or demotivating people, the question ‘which aspects of your work motivate or demotivate you?’ was used (see Table 1). Respondents could indicate three aspects that motivated or demotivated them in work.
Table 1. Questions to research value of work

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer category</th>
</tr>
</thead>
<tbody>
<tr>
<td>How important is participating in work for you?</td>
<td>Visual Analogue Scale (VAS) ranging from 1 to 10, in which 1 was indicated as ‘work is not at all important to me’ and 10 as ‘work is extremely important to me’.</td>
</tr>
<tr>
<td>For which reasons do you value participation in work?</td>
<td>Multiple choices in which respondents could indicate one or multiple answers.</td>
</tr>
<tr>
<td></td>
<td>o Because I can make myself useful</td>
</tr>
<tr>
<td></td>
<td>o Because it is a source of income</td>
</tr>
<tr>
<td></td>
<td>o Because it gives my life meaning</td>
</tr>
<tr>
<td></td>
<td>o Because it provides social contact</td>
</tr>
<tr>
<td></td>
<td>o Because it enables me to apply and develop my talents</td>
</tr>
<tr>
<td></td>
<td>o Because it improves my physical health</td>
</tr>
<tr>
<td></td>
<td>o Because it improves my mental health</td>
</tr>
<tr>
<td></td>
<td>o Because it gives me respect from others</td>
</tr>
<tr>
<td></td>
<td>o Because it gives my day structure</td>
</tr>
<tr>
<td></td>
<td>o Because it prevents boredom</td>
</tr>
<tr>
<td></td>
<td>o Other, namely ….</td>
</tr>
<tr>
<td></td>
<td>o I do not know</td>
</tr>
<tr>
<td></td>
<td>o Work is not important to me</td>
</tr>
<tr>
<td>Which aspects of your work motivate or demotivate you?</td>
<td>Open-ended question. Instruction for respondents: Regarding (de)motivational aspects, you can consider aspects related to:</td>
</tr>
<tr>
<td></td>
<td>collaboration with colleagues and managers, communication, work environment, work content, working hours, working conditions,</td>
</tr>
<tr>
<td></td>
<td>appreciation of the work and the organisation in which you work.</td>
</tr>
</tbody>
</table>

For data analysis, ‘education’ was recoded as ‘education category’, in which people with no education or people who had finished special education or specific vocational training were categorised as ‘low education’. People who had finished high school or followed intermediate vocational education were categorised as ‘medium education’. People who had completed their education at a university of professional education or university or had finished postgraduate education were categorised as ‘high education’. The reasons why people valued work were converted into 13 dichotomous variables containing the options ‘yes’ or ‘no’, indicating that respondents considered the reason for participating in work to be important (‘yes’) or not (‘no’). The demographic data, the extent to which people value work and the reasons why people valued work, were analysed using descriptive statistics (SPSS Statistics 23.0). Aspects that motivated or demotivated people in work were analysed using the MAXQDA software package (Verbi GmbH, Marburg, Germany). The answers were coded and categorized by the first researcher (MV), after which the codes were checked by the other researchers (ML, JH, HW, MF).
The study was conducted in accordance with the declaration of Helsinki. Since this study does not entail medical research and participants were not exposed to acts or rules of conduct, the research team decided that the research was not subject to the Medical Research Involving Human Subjects Act.

**Results**

Of the 4964 people who filled in the questionnaire, a total of 1683 respondents fulfilled the inclusion criteria. Of these latter respondents, 1,069 (64%) were female. The average age of respondents was 51 (SD: 10) years old. A total of 132 (8%) respondents had finished lower education, 753 (45%) respondents had finished middle education and 762 (45%) had finished higher education. 36 (2%) respondents did not answer the question regarding education. 1246 (74%) respondents had permanent employment, 139 (8%) had a temporary contract, 31 (2%) worked via an employment agency and 148 (9%) were self-employed. The remaining 116 (7%) employed people indicated ‘other’ concerning their employment status.

On a scale of 1 to 10, respondents gave work an average value of 8 (SD: 2). The reasons why people value work are presented in Figure 1. The three most frequently given reasons for valuing work are that work is a source of income (80%), work provides social contact (60%) and work makes respondents feel useful to society (52%).
Aspects that motivate and demotivate people in work are described in work-related categories, including: work content, work conditions, work relations and work environment or aspects related to personal factors or values.

With regard to work content, respondents mentioned that they enjoyed their job which motivated them. Having job-related contact with others also motivated respondents, such as having positive contact with clients or being able to help clients. Performing mentally challenging work in which the respondents were able to use or develop their talents, or performing varied and meaningful work, were reported to be motivational aspects. Doing new projects, optimizing projects, achieving goals or being successful were also mentioned as aspects motivating respondents. Some respondents reported that physical activity and moving during the day also motivated them. Finally, having autonomy over how one performs work tasks was frequently mentioned as motivational aspect. By contrast, not liking one’s job, having difficult interaction with clients or other companies, doing high mentally demanding work, performing useless and mentally undemanding work, not achieving one’s goals, and having little or no autonomy were mentioned as demotivating aspects. In addition, doing sedentary work or work that was physically demanding or repetitive were aspects demotivating respondents. Finally, bureaucracy and having to attend
many meetings were identified as demotivating.

With regard to work conditions, having an income and being financially independent were mentioned as motivational aspects, as were having flexible hours or regular working hours. The respondents also gained motivation from having a short commute to work or commuting to work by bike through nice surroundings. Aspects that demotivated respondents were dissatisfaction with one’s level of income and having fixed, long, early or irregular working hours. Having a long commute was also mentioned as a demotivating aspect.

With regard to work relations, respondents mentioned that they gained motivation from having contact with, collaborating with or receiving empathy from their colleagues or employers. They also gained motivation from being appreciated by people in their work environment. Aspects that demotivated respondents were having negative contact or experiencing negative collaboration with people in their work environment. Not receiving empathy from or not being appreciated by one’s work environment was also indicated as a demotivating aspect. In addition, receiving insufficient support or empathy from the organisation’s occupational health service demotivated respondents.

With regard to work environment, respondents stated that being satisfied with their organisation, having clear communication within the organisation, and working in a stable organisation motivated them. Having a work environment with comfortable noise and temperature levels was motivational. In addition, having adequate technical equipment to perform their work was indicated to motivate respondents, as was having a low or adequate workload in combination with sufficient rest. By contrast, being dissatisfied with their organisation, experiencing inadequate communication, and working in an unstable organisation demotivated respondents. Working in an environment with uncomfortable noise or temperature levels, or with a lack of adequate equipment, demotivated respondents. The respondents indicated that having a too heavy workload demotivated them. Finally, working alone was indicated as an aspect that could either motivate or demotivate respondents, depending on the respondent’s preferences.

Finally, with regard to personal values, respondents’ indicated that work motivated them by providing them with a structure and a goal in their lives. Being busy and having work as a distraction from their disease were
also mentioned as motivating aspects. Some respondents indicated that they viewed work as a sign of physical health, which motivated them. Various respondents indicated that they gained motivation from being able to work and therefore contribute to society. Some respondents also mentioned that work gave them a sense of self-worth and self-esteem, which motivated them. One demotivating aspect, according to various respondents, was the need to prove that one is able to perform at the same level as a healthy person. Some respondents also mentioned that limitations on their ability to work, due to the chronic disease, demotivated them in work.

Discussion
The purpose of this study was to evaluate the extent to which, and the reasons why, employees with a chronic disease value participation in work. Based on the results of this study, most respondents value participation in work. The reasons most frequently given for this were the provision of income, social contact and the ability to contribute to society. In our additional focus on how work aspects affect respondents’ perception on value of work, we found that there are several aspects that motivate or demotivate respondents in work, related either to work or to the person him- or herself.

A strength of this study is that it included a large sample of people with various chronic diseases. This means that perspectives where gathered of a large number of people irrespective of specific diagnosis. This generated new information in relation to previously performed research focusing on specific diagnosis. In addition, this study provides insight on which specific aspects motivate or demotivate people to participate in work, providing insight in which specific aspects contribute to value of participation in work. A limitation of this study is that the questions were part of a larger questionnaire distributed by patient federations. As they recruited people amongst others via social media, we have no specific insight in who they approached. Therefore, we are not aware of the response rate and are not able to tell if our sample differs from the people who did not respond.

The finding that most respondents value participation in work is supported by previous research, which concludes that people with a chronic disease perceive work as a significant part of everyday life [17,18]. With regard to the reasons why employed people value work and which aspects motivate
or demotivate them in work, many of the results reported in this study are in line with previous research focusing on facilitators for participation in work, or on the quality of work [5,10,13,14,19,20].

‘Social contact’ is one of the reasons most frequently reported by employed people with a chronic disease for why they value work. This is in line with previous research, which indicates that social contact is an important aspect of the perceived quality of work [14]. In addition, social contact, along with other themes identified in this study, such as levels of appreciation and work pressure, corresponds with important components of the well-known Effort-Reward Imbalance model [21] and the Job-Demand-Control-Support model [22]. These models explain the balance between work tasks and the available resources in order to maintain work. The correspondence between the themes identified in this study and the components of these models in which balance is key, may imply that there is also a need for balance between the aspects motivating or demotivating respondents, in order to achieve healthy participation in work.

Both the models [21,22] apply to people with or without a chronic disease. Moreover, the values reported by respondents with a chronic disease, in addition to motivating or demotivating aspects, correspond to a large extent with the values and motivating or demotivating aspects of people without a chronic disease [23]. This implies that many aspects influence work and work participation other than the chronic disease itself. This corresponds with the results of previous research [24,25,26], which shows that work participation in the chronic phase of a disease is influenced by physical, psychological, social, administrative and cultural aspects [27].

Besides the most frequently given reasons for valuing work, the respondents also reported that they valued work because it had a positive impact on their physical and mental health. In line with this, Waddell et al. [7] reported that retaining at or returning to work is associated with improved general and mental health. The effect of work on respondents’ health may be explained by some underlying motivational aspects of work, such as having a structure to one’s day, having a distraction, or being able to develop skills or abilities to work that may directly or indirectly influence one’s perception of one’s health or health behaviour. The finding that respondents consider work to have a positive impact on their health, reinforces current social attitudes regarding the ability of people with a chronic disease and guidance towards
participation in work [28].

Based on this study’s finding that most people value work, OHPs should continue to encourage and support people with a chronic disease to participate in work to their abilities. Although many of the aspects that demotivated people, such as having little autonomy, experiencing a negative work environment, and working in an uncomfortable environment, were found in earlier research to influence work participation [5,10,13,14,19,20], this study shows that these aspects can still negatively affect respondents’ experiences of work. This indicates that the knowledge gained from previous studies is not being fully utilized or implemented in society. OHPs may therefore support work participation, by discussing motivating and demotivating aspects with their clients. Results of this study can facilitate OHPs in the exploration of these aspects influencing individuals’ value of work, as preferences and (work) situation can differ per individual. Balance between these aspects can be strived to be restored through the use of interventions. In addition, OHPs could advise employers to actively support work participation of people with a chronic disease, as work environment can facilitate work adaptations which can reduce the influence of aspects depriving energy.

In conclusion, this study shows that work is generally valued by working people with a chronic disease, mainly due to the provision of income, the provision of social contact and the ability to contribute to society. Various aspects of work, related to work tasks, work relations, work environment and work conditions, were also found to motivate or demotivate respondents in work. The respondents also reported personal values as motivating or demotivating aspects.
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Declaration of interest
Author M. Vooijs, author M.C.J. Leensen, author J.L. Hoving, author H. Wind and author M.H.W. Frings-Dresen declare that they have no conflict of interest in relation to this study.

Ethical Approval
All procedures followed were in accordance with the Helsinki Declaration of 1975, revised in 2013.
References


