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How is Futures Consciousness related to the Well-Being of patients with a Chronic Health Condition?

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Abstract

People with a chronic health condition (CHC) are constantly forced to adapt their life according to their impacted physical and mental health. CHCs can change constantly and unpredictably, thus chronically ill people are confronted with an uncertain future. The CHC can aggravate emotional, social, mental, and physical matters in the life of the sufferers. For these reasons, the well-being of chronically ill people might be at risk. Additionally, it might influence how those affected make sense of their present, past and future life. On that account, this study assessed how the five dimensions of Futures Consciousness (FC) relate to the general well-being of patients with a CHC. The dimensions of FC are 1.) *Time Perspective*, *Agency Beliefs*, 3.) *Openness to Alternatives*, 4.) *Systems Perception* and 5.) *Concern for Others.* FC involves understanding, anticipating and planning for the future and was assessed by the narrative writing exercise *Letters from the Future*. The letters were qualitatively analysed by using the context-sensitive Futures Consciousness model to explore the corresponding dimensions. Researchers qualitatively examined 30 letters collected online among Dutch-speaking people with diverse CHCs and discovered a possible relatedness of FC and well-being. Chronically ill people who experienced relatively high well-being when compared to others with a CHC showed higher levels of FC, which may serve as a protective factor to keep hope even in the face of an uncertain future. Hence, further research is needed to determine the extent of their relationship. Although this study has limitations, it underscores the importance of exploring the experiences of chronically ill people and suggests integration of FC and well-being in future treatments after intervention studies took place.

Keywords

Well-being; futures consciousness; future; chronic health condition; letters from the future

Content

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1.Introduction

In the year 2030, it is expected that approximately 7 million Dutch people will have a chronic disease. This estimation would imply that 40% of the Dutch population will have a chronic health condition (CHC) (RIVM, 2014).

A CHC consists of three factors, '*(a) having a biological, physiological, or anatomical basis; (b) lasting, or expected to last, for a minimum of 1 year; and (c) producing, or very likely to produce, long-term sequelae'* (Stein et al., 1993 as cited by Holm, Patterson, Rueter & Wamboldt, 2008, p.3).

One long-term consequence can be the impacted health of a person with a CHC. Their condition can affect emotional, social, mental, and physical matters in the life of a person with a CHC (Megari, 2013). Besides the impact that a CHC can have, the gradual course of a CHC may change constantly and unpredictably and cures are rare (Esposito, 2016; Lorig, 1993). The unpredictable course of a CHC can leave sufferers facing an uncertain future and with a life that overall will be affected by their condition.

Facing uncertainty in life caused by the CHC may impact the well-being of sufferers (Ryan & Frederick, 1997). Hence, those affected may have an impacted mental and physical health (Dobbie & Mellor, 2008; Holm et al., 2008; Folkam & Greer, 2000; Stewart & Berry, 1989). Since well-being is a dynamic concept, it can change over time depending on the *balance* of psychological, social and physical resources and psychological, social and physical challenges (Dodge, Daly, Huyton & Sanders, 2012; Ryan & Frederick, 1997). If the challenges outweigh the resources imbalance can happen and the person affected needs to adapt his/her resources to meet the original challenge. This imbalance can also take place vice versa with more resources than challenges. Consequently, people must have an understanding about their CHC to anticipate future challenges, but also to identify their resources.

Chronically ill people might have to anticipate a more unpredictable and challenging future than people without a CHC. Therefore, the capacity to “understand, anticipate, prepare for and embrace the future" (Ahvenharju, Lalot, Minkkinen & Quiamzade, 2021, p. 2) may be a protective factor that helps maintain or increase their wellbeing despite being chronically ill. This capacity has been called Futures Consciousness (FC). Anticipating the future can be done by considering what is already known based on the experiences of the past and extrapolate to the future (Gilbert & Wilson, 2007). By imagining possible future scenarios would take place in the present, one can anticipate possible consequences and decide whether the consequences are positive or negative (Gilbert & Wilson, 2007).

To sum it up, CHC can have an impact on different aspects of life and on the well-being of the sufferers. These consequences combined might influence how people with a CHC look back at their past, but also affect how they assess the future.

1.1 Chronic Health Condition

According to the study of Stewart and Berry (1989) people with a CHC might be disadvantaged because they might suffer from a worse physical condition than people without a CHC. CHCs might cause stressful work conditions, social exclusion, physical ill-health violations and rapid social change (Holm et al., 2008). Especially people with more than one CHC might suffer from reductions in their overall functioning, but also in their well-being (Stewart & Berry, 1989). Moreover, people with a CHC are more likely to get a mental health condition like depression (National Institute of Mental Health, 2021). A reason for that might be the long-lasting aftermath of the CHC and its impact on the life of those affected.

Additionally, CHCs require the patients to continuously adapt to their conditions (Dobbie & Mellor, 2008). Adaptation can be a process taking place in a reactive mode, responding to immediate challenges in the present, or it could be an anticipatory process that thinks ahead to challenges to come in the future (Dobbie & Mellor, 2008). In order to adapt, people must recognise their CHC and its consequences (e.g. bodily pain) (Chabowski et al., 2017).

To sum it up, CHCs require those affected to adapt accordingly and especially factors like constant bodily pain can negatively impact their well-being (Chabowski et al., 2017). Therefore, the well-being of people with a CHC might be at risk.

1.2 Well-being in the context of chronic illness

Considering the before-mentioned definitions of CHCs and well-being, but also the required adaptation of those affected, it can be proposed people with a CHC are disadvantaged because they need to consistently adapt to extraordinary psychological, social and physical challenges, thus putting them at risk for lower well-being.

Lots of research has been conducted on the determinants of decreased well-being and also, but more limited research on protective factors (Barlow & Ellard, 2015; Slade, 2010; Folkam & Greer, 2000; Stewart & Berry, 1989). For instance, factors like social exclusion, functional impairment and/or a rapid social change caused by a CHC, having multiple CHCs, and stressful working conditions can impede the well-being of people with a CHC (Barlow & Ellard, 2006; Grootenhuis & Last, 1997; Stewart & Berry, 1989; WHO, 2018). Possessing an adequate set of coping skills to adapt to a life with a CHC, optimism, perceived social support and resilience might be promoting factors of the well-being of people with a CHC (McElroy-Heltzel et al., 2021; Treharne, Gareth, Kitas, Lyons & Booth, 2005; Johnson et al., 2014).

To sum it up, balancing resources and challenges describes positive well-being. Especially chronically ill people might be disadvantaged because they have to continuously adapt to their ever-changing CHCs.

1.3 How Futures Consciousness may be related to well-being

People with a CHC might face an unforeseeable future due to the unpredictability of their condition, which can impact their well-being and their perception of the future. FC could be a protective factor of the well-being of people with a CHC. People who are more concerned with the present than the future are more likely to make decisions that adversely affect their health and long-term well-being. (Steinberg, 2008). FC is theorized to consist of five dimensions including 1.) *Time*

Perspective, 2.) *Agency Beliefs*, 3.) *Openness to Alternatives*, 4.) *Systems Perception* and 5.) *Concern for Others* (Ahvenharju, Minkkinen & Lalot, 2018).

First and foremost, *Time Perspective* requires understanding the concept of time as well as the future. Time Perspective entails valuing long-term thinking and to be conscious of the consequences. Individuals with that skill have an understanding of the time that is passing by and are aware of the future (Ahvenharju, Lalot, Minkkinen & Quiamzade, 2021; Ahvenharju, 2018).

Additionally, it consists of the degree to which a person understands the relationship between the past, present and the future (Ahvenharju et al., 2021). Time Perspective is subjective since someone who is rather confident of his or her future scenarios would have a more expansive FC than someone living in uncertainty (Ahvenharju, 2018). One comparison which was also used by Ahvenharju (2018) is that "to think 30 years ahead in the future" has an entirely different meaning for a person who is 20 than for a 60-year-old person (p. 9). As another example, suppose a person is suffering from cancer and doesn't know how long she will live as a result of her chronic illness. Such a person may not look ahead because she believes that the future is uncertain. With regards to that example, uncertainty can restrict Time Perspective, but it can also be vice versa. It might be that the uncertainty supports time construction and conduces as a facilitator (Brown & de Graaf, 2013). People with a CHC might face uncertainties and could also benefit from the power of hope (Brown & de Graaf, 2013). Hope can help to envision a positive future and facilitate establishing resources.

Agency Beliefs is about person's views on their own is responsibility and ability to control and shape their long-term future (Ahvenharju, 2018). Agency Beliefs implies to 'have a sense of being able to influence how the future will unfold' (Ahvenharju, 2018, p.9) and to have trust in their own abilities (Ahvenharju et al., 2021). According to Ahvenharju, (2018), there is no pre-determined long-term future, rather a future that can be designed according to the agent's perceptions. It can contain the idea that the future might be influenced by taking actions in the present (Ezzy, 2000).

Additionally, Agency Beliefs contains the call to address future challenges with a more exploratory perspective and act responsibly with a long-term vision (Ahvenharju et al., 2021). It might entail the ability to accept life with CHC and its limitations, but also its opportunities. Thus, it is important to have a balanced view of what one can or cannot control. For instance, to find out what activities are still doable and enjoyable, besides having a CHC.

Agency Beliefs can be facilitated by uncertainty, even though it might overall not be a pleasant experience (Brown & de Graaf, 2013). The reason for that is that uncertainty can generate hope and might help to interpret risks (Brown & de Graaf, 2013).

Thirdly, *Openness to Alternatives* involves exploring alternatives, being able to manage and accept new alternatives which might result in personal growth. In addition to that, it entails the capability to adapt and embrace changes in life (Ahvenharju, 2018). However, embracing future scenarios also involves questioning and evaluating experiences (Ahvenharju et al., 2021).

In the context of people with a CHC, Openness to Alternatives is especially important since they are repetitively confronted with change and have to adapt to their bodily, social and psychological circumstances (Esposito, 2016; Johnson, Blum & Cheng, 2014). Thus, their future might be more unpredictable than that of people without a chronic condition, which would force them to make constant use of Openness to Alternatives. For example, people might get the chance to receive new alternative treatment methods regarding their condition, which might result in a more optimistic perception of the future (Ezzy, 2000). Hence, Openness to Alternative can be beneficial to discover new alternative treatment options that can have a major effect on their life.

Next, *Systems Perception* implies holistic and systematic thinking. It includes the perception of an individual and their identification with their belonging culture and society (Ahvenharju, 2018). Hence, realizing the relationship between human beings and other systems is as important as understanding their own responsibility within these systems Ahvenharju et al., 2021). People with a CHC might have a different perspective on the bigger picture and their perception of belonging. Those with a CHC might not feel part of society due to their possible physical or psychological limitations and/or because they do not feel accepted by society. However, it can also be vice versa, those affected might feel belonging because they realise that other people also have a CHC.

Concern for Others refers to the concept that individuals should not only anticipate their own future, but also the future of other people, of the society, and of future generations. (Ahvenharju et al., 2018). It broadens the perspective to get a bigger picture and emphasises the integration of other parties into the perception of the future.

In the case of people who are struggling with chronic health conditions, the question would be what Concern for Others looks like for them. If those affected are occupied with their own health problems or do they behave differently. For instance, it can be that they are not only concerned about themselves but also about others. However, excessive concern about everything and everyone might have an impact on their health and well-being. In contrast to that, it is also conceivable that people do not feel any concern.

1.4 Existing Research

While the way people with illness think about the future has received attention in research, a systematic investigation into how the full scope of dimensions involved in thinking about the future are used by people with chronic illness is currently lacking. Such research is needed because FC is a fairly new construct (Lalot, Ahvenharju & Minkkinen, 2021), and it enables the researcher to explore the relationship between well-being and Futures Consciousness. Further, FC might be promoting factor of awareness and active engagement with the future. Previous research indicates that people with a higher FC are more likely to communicate satisfaction, greater engagement in different forms of collective actions and higher compassion for others (Lalot, Ahvenharju & Minkkinen, 2021). Also, higher FC was associated with "greater perceived wellbeing, lesser emotional blunting, and greater feelings of hope about the future" (Lalot et al., 2021, p. 6). Consequently, people with a CHC might benefit from FC in terms of more awareness, greater perceived well-being, compassion, satisfaction and hope for the future.

The context of the research of Lalot et al. (2021) was the pandemic in which people had to face future uncertainty caused by ever-changing circumstances. The ever-changing circumstances of the pandemic and the continuously changing physical condition of people with a CHC might be comparable due to overlap of uncertainty. Because of the overlap of uncertainty, one can compare FC in the two studies and argue that there might be similar results. Consequently, it can be proposed that people with higher well-being, a more likely to express FC and are more hopeful about their future.

1.5. Research Question

To sum it up, based on prior research it can be suggested that FC might foster well-being within a context of future uncertainty inherent in living with a CHC. Therefore, this research aims at examining the relatedness of five dimensions of FC and the general well-being of people with a CHC, but also to gain in-depth insights into their overall experiences with the condition.

By inviting chronically ill people to take a step back and imagine their desired future, the researcher aims to find out how the participants make sense of their past, present and the future, but also how their well-being relate to the FC dimensions. Moreover, it aims at exploring illness-related experiences and the well-being of people with a CHC. Exploring their experiences and their desired future can be used to generate a scientific and collective understanding of living with a CHC. This understanding can be useful to improve healthcare support and detect needs of people with a CHC.

Therefore, the research question is the following:

"How are the dimensions of Futures Consciousness related to the general well-being of patients with a chronic health condition?"

2. Methods

2.1 Study Design

A qualitative study design was chosen to explore the future perspectives of people living with a CHC who differ in their experience of well-being. The study design was based on a questionnaire that consists of the Letter from the Future (Sools, 2020), the life story of the participant, the Mental Health Continuum - Short Form (MHC-SF) and demographic questions.

The Ethics committee of the University of Twente approved the study with the corresponding number 211138 before the recruitment process started. None of the participants received any compensation. The data collection was conducted between the 19th October 2021 and 9th November 2021. The researcher made use of convenience sampling to acquire participants with a chronic health condition via the online survey tool Qualtrics. Additionally, purposive sampling was utilized by the researchers who made use of their professional and private networks and approached patient organisations. Further, the survey was shared on social media platforms like Facebook, Twitter, LinkedIn, Instagram and other professional networks. Within the shared post, the URL to the questionnaire and other relevant information was provided. The post entailed information concerning the background of the study, the inclusion criteria, the exclusion criteria, contact details of the researchers, reasons to participate and information about how the data will be used. The post can be found in Appendix A. Moreover, the participant was also informed about the potential risks, but also the benefits of the study. The information was summarised in the informed consent which they had to read and sign before taking part in the study. In case of unanswered questions, the contact details of the researcher were provided.

2.1.1 Inclusion and exclusion Criteria

In order to participate in the study, people had to be at least 18 years old and be legally emancipated citizens without a guardian or legal advisor. In other words, the participant must be allowed and able to decide for himself or herself and is not restricted by for instance a legal advisor or any other psychophysical conditions that impacts their cogitation. They had to be able to comprehend, speak and write Dutch to fill out the questionnaire. Moreover, they had to possess adequate digital skills to operate the questionnaire. People were only eligible to participate if they felt able and willing to write about living with their CHC and about their present and past life and their desired future. Therefore, it was necessary that they could reflect and express their condition for the letter of the past and present, and future wishes for the Letter from the Future (Sools, 2020). Furthermore, they had to perceive themselves as living with a CHC and speaking Dutch fluently. If participants did not feel comfortable talking about their past, present and future life, it was strongly advised to not take part in the study.

2.1.3 Participants

The final study consisted of 30 participants. The researcher did not exclude any participants from the study. The sample consisted of more females (*N* = 26) than male participants (*N* = 4). The mean age of the participants was 52 and ranged from 25 to 81 years (*SD* = 14.4).

2.2 Procedure

The participants had to write one story corresponding to the instructions about (1) their short life story about past (and present) experiences with living with a chronic health condition and a letter (2) about their desired future. However, the life story will not be considered in this study design since it is part of a bigger research project and will be discussed in a different research paper. Subsequently, participants answered questions about their well-being via the standardized questionnaire about well-being, namely the Dutch Mental Health Continuum – Short Form (MHC-SF-NL). Afterward, participants filled out demographic information (e.g. gender, age, level of education etcetera) and a question about a self-classification regarding the 3 different kinds of illness narratives namely *Restitution*, *Chaos* and *Quest* (Frank, 1998). If participants had problems with using Qualtrics, they had the possibility to take part in the survey by using a Word form with similar instructions.

2.3 Materials

2.3.1 Letters from the Future (LF)

The exercise *Letter from the Future* was used (Sools, 2020) to assess Futures Consciousness.

The instructions involved imaging traveling with a time machine to a personally desired future write a letter back from the future to the present. Following that, they had to write retrospectively from the perspective of the future, and address the letter to a person in present time. Additionally, the participants could explain how they were able to achieve their desired future. The instructions contained five prompts to ensure that all necessary information will be included in the final letter. The prompts entailed 1.) the time in the future, 2.) the place in the future 3.) what role the disease plays in their life, 4.) the receiver of the letter, and 5.) the content of the message. The participants were asked to describe it as detailed and vividly as possible. All instructions can be found in Appendix B.

2.3.2 Mental Health Continuum - Short Form (MHC-SF)

Since the MHC-SF (Mental Health Continuum - Short Form) is a valid instrument to assess mental health and well-being it was integrated into this research to examine the latter. The MHC-SF arrives from the MHC-LF (Mental Health Continuum - Long Form) which included 40 items. The MHC-SF consists of 14 items and three scales. 1.) *Emotional well-being*, 2.) *Psychological well-being* and 3.) *Social well-being.* By integrating the three scales, the general well-being can be defined.

The properties of the MHC-SF were examined and evaluated by a previous research team (Lamers, Westerhof, Bohlmeijer, ten Klooster & Keyes, 2010). The instrument revealed an overall high internal reliability ($\alpha = .89$) (Lamers et al., 2010). Moreover, the subscales psychological well-being ($\alpha = .83$) and emotional well-being (α = .83) showed high reliability. The social well-being scale has proven to be adequate in its internal reliability ($\alpha = .74$). Additionally, the convergent validity and the discriminant validity of MHC-SF was tested and each was proven to be good. Every subscale measured its extended factor best. Additionally, the MHC-SF was already used in a study with patients who were suffering from a CHC and demonstrated emotional well-being (Moffatt, Hennessy, Marshman & Manickam, 2019).

The participants had to rate their answer on a Seven-Point-Likert-Scale (1 = *never*, 7 = *every day*). The items ranging from 1 to 3 belong to *emotional well-being* (e.g., “In the past month, how often did you have the feeling that you were satisfied'", while the items 4 to 8 can be assigned to the *social well-being* (e.g., "In the past month, how often did you have the feeling that you were part of a community (such as a social group, your neighbourhood , your city)?"). The *psychological well-being* scale involves the items 9 to 14 (e.g., 'In the past month, how often did you have the feeling that your life has a direction or meaning?").

2.4 Data Analysis

Prior to analysing the research data, the researcher ensured anonymity by removing any personal details about the participants. Information regarding the places, names, working places was changed by either pseudonymization or using pseudonyms. For instance, the name of the participant was removed and replaced by a label, e.g., "[first name of protagonist]" or "[city of birth]". Following that, the collected data was translated from Dutch into English by using Deepl.com. The translations of Deepl were checked and modified by a native Dutch-speaking person. Finally, the data analysis was conducted by using the program ATLAS.ti9.0.23. To find an answer to the research question *"How are the dimensions of Futures Consciousness related to the well-being of patients with a chronic health condition?"* a three-step analysis was performed:

(1) a coding scheme for qualitatively analysing FC dimensions (Sools et al. ,in press) was applied and modified. Moreover, the researcher searched for differences and similarities in terms of FC within the letters. Consequently, the adjusted coding scheme was used to analyse the letters qualitatively.;

(2) the data set was divided into two categories of participants scoring high and low on general well-being;

(3) a comparative analysis between the high and low scoring group was conducted to analyse which FC dimensions occurred predominantly in what group. Also, the number of codes for each (sub) dimension was calculated to see whether the groups showed differences or similarities.

2.4.1 Tailoring the FC coding scheme to this study

The analytical framework is based on the dimensional model of FC which derived from the unpublished manual of Futures Consciousness (Sools et al., in press) and can be found in Appendix C. The hierarchical structure and the names of the codes were adopted from the original framework. Therefore, every dimension entails subcodes that can be utilised to analyse three levels of analysis (e.g., sentence level, section level or letter level). The letter level can be used to analyse the letter as a whole. The sentence and section levels are useful to analyse smaller parts of the letter. The different levels of analysis are beneficial to detect similarities and differences across letters, but also within letters.

The basis of the coding scheme was from an iterative reflexive process which can be found in the article from Srivastava and Hopwood (2009). Thus, it was necessary to adapt the analytical framework to the context of patients with a CHC. Since it is a context-sensitive approach, the researcher first read through the letters to get an overview and explore the data. During that process, the researcher wrote down repetitive themes, which helped to identify possible codes. Then, the researcher used the initial codes to check whether they are fitting to the letters and adapted the codes until they matched the context. After reviewing and finalizing the codes, the researcher coded all letters.

Next, the extent to which the codes were tailored, will be discussed.

Time Perspective is the first dimension consisting of two sub-codes 1.) Objective Time Horizon (OTH) and 2.) Subjective Time Horizon (STH). The first sub-code can be used when the writer of the Letter concretely mentioned the date or explained how many years they want to go into the future. Also, the Objective Time Horizon derived from the original version of the framework, and it was not necessary to adapt the code. This subcode has more subcodes to categorise into short term (less than a year ahead or one year ahead), midterm (one year up to ten years), long-term (more than 10 years ahead) or unspecified (no date was mentioned). In the case of the latter, the Subjective Time Horizon might be used to identify the time based on the mentioned events in the letter. Subjective Time Horizon had to be adapted to the context. Originally this sub-code had more sub-codes, but within the pandemic setting, which was not fitting to the letters of this research. Hence, codes like “STH Within Corona” were not regarded.

Agency Beliefs is the next code, which entailed 3 subcodes. The subcodes contained the *Low/None,* the *Intermediate,* and the *High* degree of Agency Beliefs, which were adopted from the original framework. However, the descriptions of the codes were adapted to the context because it contained information that was rather inapplicable like addressing the letter to the government. The code Agency Belief is indicating the degree to which the actor takes responsibility for their actions, reflects on the consequences of the CHC to discover their limitations. Additionally, the Distribution of Agency Beliefs from the original version was not regarded because it did not match the context of this research, and the participants predominately allocated the letter agency to themselves.

The third code is *Openness to Alternatives* (OA) and is also divided by Low/None, Intermediate, and a High degree of OA. Central to that code is to visualise the future, but also accept alternative future scenarios if the circumstances may change. Besides, it is about an open and accepting attitude toward alternative future scenarios. The subcodes of the original framework were adapted to include the subject matter of the diagnosis. Also, it was important to have more subcodes than just one to cover the range of ways in which OA was experienced by the participants.

Systems Perception (SP) is divided by Low, Intermediate and High SP. By using SP, it should be identified whether people with a CHC feel part of society. Also, it is about being accepted and whether they have something to contribute to society or another social group. Additionally, the codes were adapted to the context of the letters like incorporating their CHC, and also different types of SP in terms of their feeling of being accepted within society.

The last code is *Concern for Others* (CO). Originally it contained the sub-codes “Kind of Concern” and “Degree of Concern”. However, only the latter was adopted and adapted in this research. The Degree of Concern was altered by using the following sub-codes *Low*, *Intermediate*, and *High CO*. The prior sub-code “Self-only” which also belonged to Degree of Concern, was not regarded because it did not fit the letters. Overall, the three sub-codes are aimed at broadening the perspective to see the bigger picture. It implied integrating others into the perception of the future. Thus, it is not only about being interested in their own future but also being curious about the future of others (Ahvenharju, 2018).

These dimensions (*Time Perspective*, *Agency Beliefs*, *Openness to Alternatives*, *Systems Perception* and *Concern for Others*) have been used to code the Letters from the Future. Moreover, the dimensions are not mutually exclusive, which enabled the researcher to assign multiple dimensions if applicable. Following the coding, the total number of codes per letter and per dimension was added up. Next, the distribution within the sample was regarded.

2.4.2 Creating a low and high Well-Being group

The total number of 30 letters were divided into lower and higher well-being, it is based on the general well-being score because it enables the researcher to see the bigger picture, rather than focusing on minor details. Thus, the researcher calculated the general well-being score of each letter which was explained in 2.3.2 MHC-SF. The general well-being scores were calculated, with a minimum of 5 and a maximum 60. After that, the 15 lowest-scoring participants added up to the 1.) Low well-being group and the highest-scoring participants 15 added up to 2.) High well-being group.

2.4.3. Comparative analysis step

For each code and sub-code, the frequency, as well as the content of each code, was compared between the high and low scoring group. Moreover, the researcher looked for general patterns among the participants of the high and low scoring group per dimension. Also, the researcher paid attention to similarities and differences in FC between both groups.

3. Results

3.1 Overview

The first group, consisting of the lower general well-being participants (*n* = 15), included 12 females. While the high scoring general well-being participants (*n* = 15), entailed 14 females. An overview about all characteristics of the participants can be found in Table 1.

Table 1

Characteristics of the sample distinguished by low and high well-being.

Characteristics of the sample	**Low Well-Being Group (N=15)**	**High Well-Being Group (N=15)**
Gender, N (%)		
Female	12	14
Male	3	1
Age, M	50.4	54.3
Education		
MBO	6	6
HBO	5	5
University degree	0	3
Middelbare school	3	1
Preferred not to say	1	0
Well-Being, M		
General	32.4	50.8
Psychological	24.2	15.6
Emotional	11.8	8.3
Social	15.5	9.4

Note. The table presents the characteristics of the low and high well-being group.

When considering the average age of the high well-being group ranging from 25 to 81 years (*M* = 54.3, *SD* = 15.9) it can be observed, that the participants were older than in the low well-being group (*M* = 50.4, *SD* = 12.5) ranging from 27 to 66 years.

Moreover, the high well-being participants had a slightly higher education level than the low well-being group. Both groups consist of people with each MBO (*n* = 6) and HBO participants (*n* = 5). However, the high well-being group consisted of three participants with a university degree and one participant graduated from the Middelbare school (*n* = 1). In contrast to that, the low well-being group has three participants with Middelbare school (*n* = 3) and one participant did not want to reveal their highest educational level.

Additionally, the low well-being group had a general well-being mean of 32.4 (*SD* = 9.1) and ranged from 5 to 44. The high well-being participants had a general well-being mean of 50.8

ranging from 45 to 60 and a standard deviation of 4.5. Also, the psychological well-being of the high well-being participants ranging from 21 to 29 was higher (*M* = 24.2; *SD* = 1.9) than of the low well-being group (*M* = 15.6; *SD* = 5.1) ranging from 0 to 24. The emotional well-being of the high well-being scoring participants ranging from 9 to 15 was higher (*M* = 11.8; *SD* = 2) than of the low well-being group (*M* = 8.3; *SD* =2.9) ranging from 2 to 14. The social well-being of the high well-being participants ranging from 9 to 21 was higher (*M* = 15.5; *SD* = 3.7) than of the low well-being group (*M* = 9.4; *SD* = 3.7) ranging from 2 to 16.

To conclude, most of the participants are female and possess MBO. When considering the differences between groups, great variations were observed, particularly regarding the psychological and general well-being of the participants.

3.2 Comparison of FC between high/low well-being group

In order to answer the research question "*How are the dimensions of Futures Consciousness related to the well-being of patients with a chronic health condition?"*, the overall frequency of each dimension will be displayed. Then, the results of the comparative analysis per dimension in the low and high well-being group will be presented. Also, an overview can be found in Table 2.

Overall, for this sample, the subcode unspecified of *Time Perspective* was most frequent, followed by midterm timespan, short-term Subjective Time Horizon and long-term. Next, the most coded sub-code of Agency Beliefs was the higher degree, followed by Low and Intermediate. Among all participants, the most coded code of *Openness to Alternatives* was High, followed by Low and Intermediate. In terms of Systems Perception, the sub-code High was most frequent, followed by Low/None and Intermediate. In terms of *Concern for Others* across the sample, the most frequently coded code was High, followed by Low/None and Intermediate.

Table 2

Distribution and frequency of codes per Futures Consciousness dimension

Dimension	**Code**	**Low Well-Being (*n* =15)**	**High Well-Being (*n* =15)**	**Overall Data set (N=30)**
Time Perspective				
	Short-term < 1 year	1	3	4
	Midterm 1-10 years	3	4	7
	Long-term > 10 years	1	0	1
	Unspecified	8	7	15
	Subjective Time Horizon	2	2	4
Agency Beliefs				
	Degree of Agency			
	Low/None	8	4	12
	Intermediate	4	5	9
	High	6	14	20
Openness to Alternatives	**Degree of Openness to Alternatives**			
	Low/None	8	3	11
	Intermediate	2	4	6
	High	6	25	31
Systems Perception Awareness	**Degree of Systems Perception**			
	Low/None	8	5	13
	Intermediate	3	3	6
	High	6	10	16
Concern for Others	**Degree of Concern**			
	Low	4	4	8
	Intermediate	2	2	4
	High	5	13	18

Note. The table displays the distribution and frequency of codes per Futures Consciousness dimension and general well-being group, but also across the whole sample.

3.2.1. Time Perspective

Firstly, there is *Time Perspective,* which is subjective and consists of understanding the relationship between the past, present and the future, but also entails long-term thinking (Ahvenharju et al., 2021). Regarding the differences and similarities between the groups, it can be observed that most of both groups did not specify the date of the future. However, some participants just wrote down the exact date *"01 January 2022",* while others clearly stated how many years into the future they imagine themselves "*My future takes place when I am 34 years old, so in 10 years.*", which belongs to the short-term code. Hence, some minor differences between both groups were found.

The high well-being group showed a greater number of the sub-code "1 to 10 years into the future (*n* = 4), than the low well-being group (*n* = 3). Moreover, no one in the high well-being group had a long-term imagination of the future. In contrast to that, there was one participant in the low well-being group who looked up "10 to 20 years from now". Another example would be one high well-being participant who described that their daughter is pregnant with twins, and she started the letter like the following "*To my future girl twins*". Hence, one can suggest that the person is envisioning a future that is approximately 0 to 9 months ahead.

As a conclusion, no clear patterns were found to differentiate between low and high well-being groups with regard to Time Perspective.

3.2.2. Agency Beliefs

Secondly, *Agency Beliefs* are defined by person's perception of their own is responsibility to control their long-term future and it can also involve the acceptance of a life with the CHC (Ahvenharju, 2018). If considering the differences between both groups, it is striking that the high well-being group (*n* = 8) has as twice as many codes regarding the high Agency Beliefs as the low well-being group (*n* = 4). High well-being participants showed a tendency that they accept their CHC. For instance, one participant of the high well-being group describes the role of the CHC as the following:

> *"Yes, it is still there. But I can handle it better because I have been able to get more peace in other areas. Because I have been able to get more peace and quiet, I am more myself again, more cheerful, more impulsive and more worthy of my family."*
>
> - MBO, 56 years, female

This person accepted that her condition might stay ("*Yes, it is still there. But I can handle it better")*, and she probably found techniques or more like herself with more inner peace and finds rest if needed. Thus, she is demonstrating a great sense of Agency Belief.

Additionally, by addressing her family, she shows concern for others. It seems that her family is very dear and close to her. That might be because her family shows support or encourage her, but also other positive influences are conceivable. In addition, high well-being participants seemed more accepting of their physical limitations than the low well-being group. Moreover, some high well-being participants not only accepted their own physical limitations but also went a step further by perceiving their condition as a part of themselves. They feel complete as they are, also with regards to their CHC.

> "*The condition, the amputation of my left arm, is visible and will remind me of what it took to get my life back, to become healthy again. I am independent and do not miss the arm. I feel like a complete person in all respects*."
>
> - HBO, 54 years, female

After reading that excerpt it can be claimed that the amputated arm can be viewed as a metaphor for her success to become healthy again. Additionally, it can be argued that people who have accepted their CHC and perceive it as part of themselves might have higher well-being. This would also be in line with a statement from another participant who described her CHC as fog.

> ” *After all these years, I've decided that I love the fog, that it belongs to me. As a result, I no longer experience the fog as an enemy but as something that belongs to me, and sometimes I'm even glad. [..] there's nothing else wrong with me.*”
>
> -HBO, 73 years, female

However, people with low well-being were also able to accept and enjoy their condition: “*I like it like this. I am already used to it*”. That person is not only accepting her CHC, but she is also enjoying her current condition. Contrary to that, instead of accepting the CHC some participants of the low well-being group wished for a cure for their condition (e.g., *“Dear family and friends you will not believe it but I am cured*”). This excerpt provides the idea that the participant does not want to include her CHC in her future and rather focuses on a life without a CHC than accepting her condition. It can be suggested that the person has difficulties accepting and handling her CHC, which is the reason she envisions a future in which she feels capable of managing her life.

To sum it up, the high well-being group seemed to be more accepting of their limitations caused be the CHC than the low well-being group. Moreover, some high well-being participants not only accepted their condition, but they also made clear that the CHC is now a part of themselves.

3.2.3. Openness to Alternatives

Thirdly, there is the *Openness to Alternatives,* which entails the capability to adapt, accept and embrace changes in life (Ahvenharju, 2018). Regarding the differences and similarities between the groups, it can be noted that there was a tendency among the high well-being group to score higher on Openness to Alternatives than the low well-being group. Moreover, most of the high well-being participants planned in the future, strived to think about alternatives future scenarios, and rarely mentioned their old future scenarios. People with lower well-being also demonstrated Openness to Alternatives. For instance, the next participant understands the origin of her CHC and clarifies what role the CHC plays in her future.

With regards to what role CHCs plays in her future, the participant explained "*they no longer dominate my life as they do now"*. Further, she accepts her condition as it is ("*The conditions I have are chronic and partly genetic. They are part of me.").* Also, it seems that the acceptance of her condition might lead to a broadened horizon ("[..] *then my horizon is broader and sunnier again.")*. That is why it can be argued that acceptance, Agency Beliefs and Openness to Alternatives might relate to each other. In addition, that person belongs to the low general well-being group and is open to alternative future scenarios. With the next excerpt the same participant is evaluating one alternative future scenario that might help to live a more pleasant life:

> *"But that it will always be tomorrow and that there will be new plans, ideas, medications and treatments that will help you to live again."*
>
> -MBO, 36 years, female

The 36 years old participant evaluates her future, but also expressed hope by saying there "will always be a tomorrow and "new plans, medications and treatments that will help".

People with higher general well-being perceive possible difficulties in the future as opportunities to become stronger. Further, the participant clearly underlines and embraces new alternative future scenarios or also called new routes as in her quote:

> *"There may be difficulties on your path but you can overcome them and it will make you stronger. I see me having faith in life, overcoming my fears, making jumps and discovering new routes. These paths are endless and there is always help along the way"*
>
> - HBO, 54 years, female

By mentioning "having faith in life, overcoming fears [..] and discovering new routes", she conveys lots of hope and expresses optimism regarding her future, despite having fears. When comparing the excerpt of the 36 years old and the last one, there is an overlapping theme regarding having hope in the future, despite the CHC. Besides that, one participant of higher scoring group is actively striving to expand her perspective and world. Also, she wrote lots of reflective statements about herself and visualises possible her desired future.

> *“I would love to be part of a team of wedding planners. I would love to be part of it as a photographer, creative collaborator, to help a couple organise the day of their life. [..] I already take beautiful photos and I'm very creative and have great empathy. Being out of work still saddens me daily. I am a very social person and would like to expand my world. By being allowed to work in a team, where they accept me with my disability, I can best bring my work to a good and beautiful result. [..] This opportunity would help me to stand more firmly on the ground.“*
>
> -HBO, 51 years, female

After reading the excerpt one might argue that she evaluated future scenarios and imagine what effect the future might have on her self-image. She addresses also other codes like Systems Perception (“[..] to work in a team, where they accept me.”) and Concern for Other (“to help a couple organise the day of their life”).

To sum it up, the majority was open to alternative futures by accepting the underlying circumstances, but the low well-being group tendentially showed a lower degree of Openness to Alternatives than the high well-being group.

3.2.4. Systems Perception

Fourthly there is *Systems Perception,* which involves the individual’s belonging with culture and/or society (Ahvenharju, 2018). When considering the between-group results, it stands out that there is a higher number of the code high degree of Systems Perception (n = 9), in the high well-being group than in the low well-being group (n = 5). In addition, in the latter, there are more cases of low/none Systems Perception (n = 8) than in the high well-being group (n = 4). Besides that, a participant achieved both high and low scores on the Systems Perception test in the same letter. One can identify the different level of Systems Perception in the two following excerpts.

> “*I will continue to work in the museum when it is open. I do this for my colleagues and especially for the visitors. This often leads to interesting conversations about lithographs, but also about related or completely different subjects.”*
>
> - HBO, 66 years, female

It can be suggested that she enjoys being part of the staff (“*my colleagues*”) in the museum and she appreciates the conversations with her colleagues and visitors (“*This often leads to interesting conversations”*). By embracing the socialisations and being part of a group this indicates a high sense of Systems Perceptions, but also Concern for Other because of saying “I do this for my colleagues and especially for the visitors”.

In the following, the same participant might indicate a lower Systems Perception:

> *“[..] if you 'don't participate' you are not appreciated positively either. Even your best friends can't really understand this, unless they themselves have been affected by a chronic illness. Or NAH. But even then, views and illusions differ. Sometimes someone suddenly gets respect. And the lack of interaction (silence, not asking questions) often makes me feel excluded.”*
>
> - HBO, 66 years, female

Contrary to the previous quote, she explains that she often does not feel like a part of society (“*makes me feel excluded”),* although she indicated that she is contributing to her group. Hence, it can be guessed that contributing something to society does not mean, that one certainly feels accepted and as part of a certain group. Also, people with a CHC might not always feel Systems Perception and it might change depending on the circumstances.

To sum it up, it seems like lots of high well-being and some low well-being participants feel belonging to the society and contribute something to their social group by sharing their experiences.

3.2.5. Concern for Others

Fifthly, there is *Concern for Others,* refers to the thought that people should not only anticipate their own future, but also the future of other people, of the society, and of future generations. (Ahvenharju et al., 2018).

When considering both groups, it can be stated that there is a clear tendency that the participants of the high well-being group have more often expressed their Concern for Others (*n* = 13) than the participant from the low well-being group (*n* = 5). Low Concern for Others (*n* = 4) had the same amount in both groups, and likewise Intermediate Concern for Others (*n* = 2). However, also people with low well-being feel concerned for others as the next excerpt shows:

> *"I would like to assist others in their processes with the same. I can help them with their questions, offer treatments, knowledge and experience in dealing with the needs of their own individual*
>
> - MBO, 57 years old, female

That participant seems to be concerned with fellow suffers ("*I would like to assist others in their processes") and offers her help with their questions or treatments ("I can help them with their questions, offer treatments, knowledge and experience [..."]).* Hence, people can feel "Concern for Others", even when their well-being is rather low. Another example of Concern for Others, but from the high well-being group is the following *"For a long time, I took care of you one day a week and that makes our relationship so special.*". That participant suffers from Lichen sclerosis and is still envisioning taking care of her grandchildren. Hence, that sentence can be classified as a higher degree of CO. There are also other examples in which a higher well-being participant also addressed their letter with "Dear fellow-sufferers" to establish a connection to people with a similar condition.

Additionally, it is also possible to express Concern for Others by asking questions like the next participant of high well-being group:

"I look forward to our little chats. A different theme each time. My theme now is Lichen Sclerosis. [..]. As you already know, Granny has this.[..] Are you already having sex with your friends? [..] How does it feel? Does it hurt?[..] The verdict of being twins is that you talk about everything Catch each other, discuss things... make your sharing group bigger. I have been a one-woman fight too much and too long. And was often frustrated as a result."

- University degree, 67 years, female

This participant uses her prior experiences to create awareness and encourage the unborn twins to think and talk about sex. She is encouraging them to find out whether it is a pleasant or unpleasant experience. Moreover, that participant tried to talk about that topic to explain her CHC and do some educational work. By doing that she is sharing her concern and maybe even want to protect them against negative experiences. That excerpts indicated a high degree of Concern for Others since the participant is considering unborn generations and appeals to the girls to talk openly and freely with each other about any experiences. Also, she motivates them to share their opinions in a bigger group to not be single-woman fighting, as she was. Hence, her grandchildren can learn from her life experiences and find more suitable ways to deal with a CHC or problems.

Participants conveyed their Concern for Others by expressing their wish for more explanatory work. Sharing knowledge and experience can protect others and prevent them from making similar mistakes. In addition, explanatory work could transform the topic of CHC into an ordinary theme, which is as common and known as brushing teeth ("*What a joy that caring for LS is as normal as brushing teeth!").*

"There is no shame, everyone now knows what Lichen Sclerosus is and how you can recognise it. Men with LS also speak openly about their illness and, very remarkably, even children who have LS know about it. [..] What a joy that caring for LS is as normal as brushing teeth!"

-HBO, 65 years, female

To sum it up, sharing experiences was evident while showing *Concern for Others*. Many high well-being and fewer low well-being participants reported their experiences with the motive to help others with similar CHCs and strive to answer questions about their condition to raise awareness.

4. Discussion

This research paper examined how the dimensions of Futures Consciousness relate to the general well-being of patients with physical CHCs. There was a tendency that participants with higher well-being expressed a higher degree of the FC dimensions (*Concern for Others*, *Systems Perception*, *Openness to Alternatives* and *Agency Beliefs)* than the participants with lower well-being. However, *Time Perspective* was not a distinguishing factor.

When a group mostly demonstrated "high" and not "low" sub-codes, one can speak of higher levels of FC. Based on the counting frequency of subcodes, people with relatively high well-being showed more often higher than the lower or intermediate sub-codes. Thus, it can be suggested that the high well-being participants of this study had higher levels of FC, both quantitatively and qualitatively. In contrast to that, people with relatively low well-being demonstrated more often “Low” FC dimensions, thus it can be suggested that the low well-being group lower level of FC.

4.1 Interpretation of the findings

4.1.1 Time Perspective

Considering *Time Perspective*, many participants did not mention any date or defined a clear time frame in the future. A possible explanation might be that the future can be associated with anxiety, which led participants to not specify the exact time frame (Eysenck, Payne & Santos, 2006). Not knowing and neither foreseeing what the future will bring relates to being anxious and might seem frightening. In that case, the unknown future seems like a blank space and if a person is then expected to limit the future, one can experience more difficulties. If this person also has a chronic illness, which is uncertain and unpredictable, the future can be even less predictable than it already is. For that reason, people with CHC may find it difficult to determine the exact time of the uncertain future, which was also observed in this study. Another alternative explanation might be that the participants missed the prompts, thus did not include the exact time.

In addition, the results of this study contribute to the theory which suggests that Time Perspective is subjective (Ahvenharju, 2018). Depending on the circumstances of a person's life one looks into the future differently, ranging from looking 'less than a year' (short-term-thinking) out to looking 'more than 10 years' (long-term-thinking) out. Aside from the sub-code ‘unspecified’, there was a tendency for people with a CHC to imagine their future to be ‘1 to 10 years’ (midterm thinking) into the future. This tendency can be suggested as the approximate time frame for people with similar circumstances (e.g. chronically ill people) when they are imagining their future.

To sum it up, most participants did not mention a time frame, which might relate to the great amount of uncertainty in their future or that the participants missed the prompts. However, despite their uncertainty, participants were capable of long-term thinking, midterm, and short-term thinking. Thus, the varying time frames underlined the subjectivity of Time Perspective.

4.1.2 Agency Beliefs

Agency Beliefs can be defined by people that have a balanced view of the factors they can or cannot influence in the future. People with higher well-being, scored higher in Agency Beliefs than people with lower well-being. This difference might be attributed to the acceptance of the CHC. The participants of this study with higher well-being found ways to accept their condition, and made peace with their illness, which could relate to their well-being (Ranzijn & Luszcz, 1999). Accepting might involve understanding the CHC with its limitations, but also its opportunities. Understanding and accepting the extent of the CHC can help to identify attainable goals for their desired future and gives them a feeling of agency. Moreover, agency may be associated with trust in their own abilities and higher well-being (Ahvenharju et al., 2021).

In contrast to that, people who are struggling to accept their CHC might have unattainable goals and plans, or unrealistic perceptions. For example, it may be unrealistic to want to do the same activities as when you were completely healthy. Living with outdated ideas despite changing life circumstances can be linked to lower well-being and agency (Wrosch, Scheier, Miller, Schulz & Carver, 2005). Hence, chronically ill people who are still very attached to old ideas about the future that they had before their diagnosis, might need some time to accept their CHC and understand how their future is impacted by their condition.

In addition, social support can be seen as a promoting factor when confronted with health problems (Lu & Hsu, 2013). Therefore, it is conceivable that chronically ill people could find rest and peace by spending time with their families or other significant others. Social support might also include that the significant others reinforce the independence of the other person. Moreover, social support might enable communal agency, indicating the idea that a person does not have to do everything on their own and can rely on the help of others. When considering the findings, one can propose that especially high well-being participants might profit from an encouraging social support system, which might relates to their higher Agency Belief and well-being. However, it can also be the other way around. People received social support, which is the reason why they might feel more agentic and capable to accept or manage their illness. In contrast to that, people without social support might be left without any encouragement and must manage all difficulties on their own, which can be associated with lower well-being.

To conclude, accepting CHC with its limitations, but also its opportunities might relate to higher Agency Beliefs. In contrast to that, living up to old future goals may relate to lowered well-being and Agency Beliefs. Social support and communal agency might be associated with higher Agency Beliefs because of possible encouragement from significant others.

4.1.3 Openness to Alternatives

People from the low well-being group showed a lower degree of Openness to Alternatives, while high well-being participants tended to be more open and appreciating regarding their alternate future. Openness to Alternatives was the most commonly used dimension across the whole sample and especially among the well-being group. This frequency may highlight the significance of the dimension for people with a CHC.

The divergences between the well-being groups might be explained by looking at the trait openness. It can be argued that people who score high on Openness to Alternatives, also possess the trait openness, which helps them to adapt, accept and embrace changes in life (Ahvenharju, 2018). People with greater openness "are more willing to accept new ideas, to perform new behaviors, or to change habits, which may improve their functioning in individual life" and their well-being (Lamers et al., 2012, p.5). However, the relation between well-being and Openness to Alternatives can also be vice versa. People with higher well-being might find it easier to accept alternatives and adapt to their CHC. This can be attributed to the balance of resources and challenges. High well-being participants might have found great ways to use their existing resources and build new ones to manage the ever-changing CHCs, which can relate to higher Openness to Others.

Additionally, Openness to Alternatives might be related to Agency Beliefs. The dimensions might overlap because both concepts entail evaluating. For instance, it is necessary to question and evaluate experiences to accept alternative future scenarios (Openness to Alternatives). Moreover, to accomplish a balanced view one must evaluate limitations and opportunities, but also capabilities (Agency Belief). Agency Beliefs might be helpful when confronted with multiple alternatives and trying to weigh up which one is the best.

People with a CHC must face ever-changing circumstances and alternatives. Thus, they might benefit from a balanced view from the Agency Belief dimension. Agency Beliefs involves taking an explorative perspective, addressing challenges with responsibility and long-term thinking (Ahvenharju et al., 2021). Moreover, taking a balanced view can help to face different scenarios because, no matter the circumstances, the individual still knows his/her capabilities, but also identifies factors beyond the individual's control. This might help to develop trust in their own abilities and to feel agentic.

To sum it up, the divergences between the low and high well-being group might be explained by the trait openness, which might relate to Openness to Alternatives and well-being. The interrelatedness of Openness to Alternatives and Agency Belief can be identified by overlapping themes and complementary issues.

4.1.4 Systems Perception

On the dimension *Systems Perception*, people with higher well-being showed to a greater extent that they feel part of society and contribute something to their social group. In contrast to that people with lower well-being fairly felt a sense of belonging and seemed more concentrated on themselves.

Social support, contribution, and belongingness are promoting aspects of Systems Perception (Ahvenharju, 2018). However, the social well-being of the low well-being group was rather low when compared with the other group. The low well-being participants might not have a social group and did not have the chance to feel belongingness. The absence of belongingness and the presence of loneliness can relate to lower well-being (Golden et. Al., 2009). Therefore, people with lower Systems Perception might wish to be part of a social group in which they feel belonging. Further, lack of belongingness and Systems Perception can be associated with their lower well-being, which is in line with the following quote “as Aristotle said, humans are social animals, or as I would say, humans are social beings” (Fiske, 2018, p.11). Accordingly, humans might need socialisation and belongingness to feel well. Especially people with a CHC need social support as a resource by drawing strength from it, which they might need to manage their impacted health. (Maguire, Hanly & Maguire, 2021).

In addition, it is important to point out that the original description of Systems Perception was more focused on natural systems and how humans recognise the interconnectedness between them, and also to realise the consequences of actions (Ahvenharju et al., 2021). In the context of chronic illness, the social and societal system may be more important for the Systems Perception than the natural environment. Therefore, the focus of the definition adapted to the belongingness of people in society and anticipating the consequences of actions. It can be argued that by adapting the definition some aspects of FC may not be as present as in the original research. However, by tailoring the definition the results got more meaningful and useful for people that face uncertainty (e.g. having an unpredictable course of CHC). For instance, the results showed that people without belongingness can feel less well (Van Ryzin, Gravely & Roseth, 2009) and might display lesser Systems Perception.

To conclude, by changing the focus of Systems Perception, the researcher gained insight into how chronically ill people's well-being is related to their sense of belonging. According to the results, Systems Perception in terms of belongingness might be related to higher well-being and can be perceived as a resource for people with a CHC, while a lack of Systems Perception might be associated with lower well-being.

4.1.5 Concern for Others

When reflecting on *Concern for Others*, there was a noticeable difference between low well-being and the high low well-being group. Participants with higher well-being showed a greater Concern for Others and demonstrated their concern by asking questions or sharing experiences.

Participants were concerned for other people beyond their immediate circle of family and friends. For instance, they expressed great empathy for people with similar chronic conditions and wanted to use their experience with CHC to help others. People who feel ‘Concern for Others’ and want to help others might have an altruistic motive. Altruism is associated with greater well-being, longevity, and health (Kahana, Bhatta, Lovergreen & Midlarsky, 2013; Post, 2005). Hence, the participants who scored high on this dimension, might had altruistic motives which increased their well-being. Contrary to that, people with altruistic concern who mostly focus on doing tasks and favours to please others might forget their own well-being. Therefore, if a person is constantly trying to make other people happy, while ignoring their own needs and desires, their well-being might be impaired. Moreover, acting submissive may also be part of altruistic behaviour and contributes to reduced well-being (Connor, Berry, Weiss & Gilbert, 2002). Further, excessive altruistic concern for others relates to depression (Connor et al., 2002). Since people with a CHC are already at risk for psychological distress and depression, excessive altruistic concern cannot be beneficial. Consequently, low well-being participants who showed altruistic Concern for Others may overly focus on others instead of themselves, which could relate to their lower well-being

4.2 Strengths and Limitations of this study

This study entails a distinctive combination of FC and well-being in the context of people with a CHC. A strength of this research is that participants were asked to anticipate their desired future in the light of their past, thus creating a bridge between the past and the future. Imaging the desired future might give people a sense of control and/or agency over their life, which is especially relevant for people with a CHC since their condition is affecting many aspects of their life. This anticipation can be beneficial for patients with a CHC to become more future conscious and accepting towards their CHC. Further, in this chosen context FC might protect people with a CHC against emotional blunting and facing unpredictable future scenarios (Lamers et al., 2021).

Besides that, a limitation is that the researcher did not consider different types of CHCs. CHCs can have a wide variety of effects and consequences for those who suffer from them (Stewart & Berry, 1989). Therefore, considering the type of CHC might reveal additional information about the relatedness of FC and well-being. For instance, diseases that have a severe impact on the lives of those affected, such as heart-related diseases, may be important to consider in future research (Holm et al., 2008). Moreover, the sample of this research consisted of participants with similar characteristics (e.g. high level of education, middle-aged, Dutch-speaking). Since culture significantly impacts disease risks, worldviews and lives (Barton & Yang, 2000; Dressler, 2000; Lefley, 1990) and a higher level of education can promote physical and psychological health (Schagen & Lawes, 2009) a more diverse sample could provide additional information. The limitation is also consistent with Ahvenharju (2018), who was aware of cultural contexts.

4.3 Implementation and future research

This study assessed a potential positive association between FC and well-being in the context of people with a CHC. However, it was not examined whether FC predicts or promotes well-being or vice versa. Moreover, it is not clear how strong the relationship is. Therefore, it leaves the question of the kind of interdependence of well-being and FC open for future studies.

As described above, this research would have benefited from a more divergent sample, while considering different types of CHCs. Hence it is suggested to reproduce this study but with a divergent and greater sample, which can enable greater insights, and answering questions like what culture promotes which FC dimension. How does well-being differ within a sample with different nationalities and levels of education? Is Openness for Alternatives also the most frequent dimension within different contexts? There are still lots of unanswered questions regarding FC, therefore, further theoretical elaborations and refinement are recommended.

The usage of the Letters from the Future was initially used for people with mild depressive symptoms to promote FC and already demonstrated its practicability (Bohlmeijer, 2007 as cited in Sools, 2020). Moreover, if future intervention studies showed that FC promotes well-being, it might be beneficial for patients with a CHC to integrate these concepts by using Letters from the Future in treatments. Integrating FC in treatments might help those affected with the acceptance of their CHC, but also encourage patients to confront their future goals and plans. Pursuing attainable goals might improve their well-being and provide those affected give them a sense of control over their life and their CHC.

4.4 Conclusion

FC can be considered as a descriptive and normative construct. The study showed a tendency that the high well-being group has a higher and a more advanced version of FC, while the low well-being group scored lower on FC. Most of the FC dimensions (*Concern for Others, Systems Perception, Openness to Alternatives and Agency Beliefs*) were found to be distinguishable factors between both groups, with the exception of *Time Perspective*. Openness to Alternatives appears to be important for people with CHC because of the observed frequency. Overall, the results of this study suggest a mutually reinforcing relationship between well-being and FC, but further research is recommended.

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6. Appendix

Appendix A

Informatiebrief voor deelnemers aan het onderzoek "Hoe mensen met een chronische aandoening verhalen over hun verleden en toekomst" Fase 1: een verhaal en brief schrijven

Welkom!

Welkom bij ons onderzoek naar uw verhalen over het verleden en de toekomst!
Dit onderzoek is bedoeld voor volwassenen met een **chronische aandoening**. Dat is een aandoening die langer dan een jaar duurt en medische aandacht vraagt of het dagelijks leven beperkt. Herkent u zich daarin? Dan nodigen we u uit om deel te nemen aan het onderzoek.
Kent u iemand met een chronische aandoening? **Stuur** deze informatiebrief dan **gerust door.**

Wie doen het onderzoek?

Het onderzoeksteam bestaat uit:
- Anneke Sools, hoofdonderzoeker: universitair docent aan de afdeling Psychologie, Gezondheid en Technologie van de Universiteit Twente.
- Jacqueline Coppers: onderzoeksassistent aan de Universiteit Twente en ergotherapeut.
- Henriette Höhne en Sarah Mertins: Master-studenten Psychologie aan de Universiteit Twente.

Wat is het doel van het onderzoek?

Wij zijn geïnteresseerd in hoe mensen verhalen vertellen over hun **ervaringen** met een chronische aandoening. Ook zijn we benieuwd naar de **toekomstwensen** van mensen met een chronische aandoening.
We willen weten hoe hun ervaringen en toekomstwensen samenhangen. Deze kennis kan helpen om meer inzicht te krijgen in ervaringen van mensen met chronische aandoeningen. Door hun hoop en dromen voor de toekomst te leren kennen hopen we mensen met een chronische aandoening een stem te kunnen geven. Om daarmee uiteindelijk verbeteringen voor te stellen voor de zorg aan mensen met een chronische aandoening.

Wat verwachten we van de deelnemers?

We verwachten van u als deelnemer dat u:
1. een **verhaal** schrijft over uw leven met een chronische aandoening.
2. een **brief** schrijft over uw wensen voor de toekomst.
3. enkele **vragen** beantwoordt over uzelf, over uw verhaal en over uw chronische aandoening.

En verder:

U kunt op elk moment stoppen met het onderzoek, zonder een reden te geven. U bepaalt zelf hoeveel **tijd** het u kost. We verwachten dat het ongeveer **45 minuten** kost. Maar u kunt zoveel tijd nemen en zoveel **pauzes** nemen als u wilt. U kunt ook tussendoor stoppen en later weer doorgaan, want de antwoorden worden tussendoor bewaard.
U beantwoordt de vragen in uw eigen tempo, liefst voor **half november 2021**.

Wat zijn de voors en tegens van deelname aan het onderzoek?

Voors:
- Sommige mensen vinden het fijn om hun verhaal te delen met anderen. Ze vinden het fijn dat er naar hun verhaal geluisterd wordt.
- De ethische commissie van de Universiteit Twente heeft het onderzoek goedgekeurd.

Tegens:
- Niet iedereen vindt het fijn om zijn verhaal te vertellen.
- Het kost u tijd en inzet om uw verhaal en brief te schrijven en om de vragen te beantwoorden.

Wat doen we met uw antwoorden?

Wij, het onderzoeksteam, verwerken de antwoorden **anoniem**, dus zonder uw naam of andere persoonlijke informatie te gebruiken. Want we willen dat niemand weet dat de informatie over u gaat. We gebruiken de anonieme informatie voor een artikel in een wetenschappelijk tijdschrift, of voor een presentatie op een congres.

Hoe bewaren we uw persoonlijke informatie?

We bewaren uw persoonlijke informatie op een **veilige plek**, apart van de gegevens van het onderzoek. Alleen het onderzoeksteam heeft toegang tot de onderzoeksgegevens en uw persoonlijke informatie.
We moeten de anonieme onderzoeksgegevens 10 jaar bewaren.
Want als het nodig is, dan moeten andere onderzoekers de anonieme resultaten van het onderzoek kunnen controleren.

Wilt u meedoen?

Dan kunt u terugkeren naar het onderzoek. De link naar het onderzoek is:
https://utwentebs.eu.qualtrics.com/jfe/form/SV_eE6AAihR3CwUAIu

Wilt u ons verder helpen?

Dan kunt u (andere) mensen die leven met een chronische aandoening uitnodigen om deel te nemen aan dit onderzoek.

Heeft u nog vragen?

Mail, bel of sms dan gerust met Jacqueline Coppers via emailadres: [e-mail address] of telefoonnummer: [phone number].

Appendix B

Q1
Onderzoek
“Hoe mensen met een chronische aandoening
verhalen over hun verleden en toekomst”

Welkom bij het onderzoek "Hoe mensen met een chronische aandoening verhalen over hun verleden en toekomst". Wat fijn dat u mee wilt doen aan dit onderzoek!
Het onderzoek bestaat uit de volgende onderdelen:

1. uw **verhaal** schrijven over uw **leven met een chronische aandoening** (maximaal 1 A4),
2. een **brief** schrijven over uw **gewenste toekomst** (minimaal 1/2 A4, mag ook meer)
3. een **vragenlijst** invullen.

Het onderzoek duurt **ongeveer 45 minuten.**
U kunt tussendoor stoppen en op een later moment verder gaan, uw antwoorden worden tussendoor opgeslagen.
Heeft u nog vragen? Dan kunt u contact opnemen met Jacqueline Coppers, door te mailen naar: [mail address] of te bellen of te sms-en (phone number).

Door op onderstaande knop te klikken verklaar ik dat

ik 18 jaar of ouder ben
ik weloverwogen heb besloten om deel te nemen aan het onderzoek “hoe mensen met chronische aandoeningen verhalen over hun verleden en toekomst”
ik de informatiebrief voor deelnemers heb gelezen (zie Informatiebrief verlenging verhalen chronische aandoening universiteit twente)
ik begrijp dat ik mijn deelname op ieder moment en zonder opgave van reden kan stoppen
ik begrijp dat mijn persoonlijke informatie (naam en contactgegevens) vertrouwelijk wordt behandeld, beveiligd wordt bewaard en geanonimiseerd wordt voorafgaande aan de data-analyse
mijn deelname aan het onderzoek vrijwillig is.

○ ik ga hiermee akkoord en ik wil starten met het onderzoek (1)

○ ik ga niet akkoord, ik wil niet deelnemen aan het onderzoek en ik stop (2)

Q23 U bent nu aan het einde van de vragenlijst gekomen.

Mocht u ons verder willen helpen dan kunt u dat op verschillende manieren doen:

1. door **anderen** (mensen die leven met een chronische aandoening) **uit te nodigen om deel te nemen** aan dit onderzoek.

2. door uw **gegevens beschikbaar te stellen** voor deelname aan het **vervolgonderzoek** (fase 2). In fase 2 worden een aantal deelnemers van fase 1 uitgenodigd voor een interview. In dit interview wordt het onderwerp leven met een chronische aandoening verder uitgediept.

Om uitgenodigd te worden voor deel 2 kunt u dat hieronder aangeven of ons een email sturen waarin u aangeeft graag uitgenodigd te worden voor een interview.

Het emailadres zal alleen gebruikt worden om u uit te nodigen voor het interview in fase 2. Uw gegevens worden apart anoniem en vertrouwelijk verwerkt.

○ Ja, u kunt contact met mij opnemen voor de vervolgstudie. Mijn emailadres is (1)
____

○ nee, ik wil niet meewerken aan een interview in fase 2. (2)

Q2 Wilt u in het lege veld hieronder uw verhaal schrijven over uw leven met een chronische aandoening (verleden)?

Wilt u uw verhaal vertellen hoe het met u is gegaan sinds bekend werd dat u een chronische aandoening heeft? Beschrijf met **zoveel mogelijk details** wat u tot nu toe heeft meegemaakt en **hoe u zich daarbij voelt**. Misschien heeft het uw leven veranderd. Bijvoorbeeld op het gebied van gezondheid, wonen, werk of andere activiteiten, sociale relaties, andere levensgebieden of het beeld over uzelf. Of misschien ook niet.
We zijn geïnteresseerd in uw eigen **persoonlijke ervaring**. Het gaat dus om uw eigen beleving.
Het schrijven van een verhaal over uw leven met een chronische aandoening zal ongeveer **15**

minuten kosten. Sommige mensen hebben meer tijd nodig en sommigen minder. Neem alle tijd die u nodig heeft. Het gaat om een verhaal van **maximaal 1 A4**.

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Q3 De volgende vraagt gaat over de **stijl van uw verhaal** over uw leven met uw aandoening.

Socioloog Arthur Frank onderscheidt 3 verschillende manieren waarop mensen vertellen over hun aandoening of ziekte, namelijk:
a. **Restitutie** (genezing, herstel) is het verhaal van "ik werd ziek, ik leed, ik werd behandeld, maar ik ben genezen door de behandeling".
b. **Chaos** is het verhaal van "mijn leven is onzeker, ik leef op de bodem, een diagnose blijft uit, de behandeling heeft geen effect, ik weet niet hoe het verder moet".
c. **Queeste** (zoektocht, beproeving) is het verhaal van "ik heb een nieuw perspectief op mijn leven gekregen, ik ben een andere persoon geworden".

In welke van deze drie manieren van kijken herkent u zich?

○ Voornamelijk in a. Restitutie (1)

○ Voornamelijk in b. Chaos (2)

○ Voornamelijk in c. Queeste (3)

○ Een mix van a. Restitutie en b. Chaos (4)

○ Een mix van a. Restitutie en c. Queeste (5)

○ Een mix van b. Chaos en c. Queeste (6)

○ In alledrie (a. Restitutie, b. Chaos en c. Queeste), en wel in deze volgorde van belangrijkheid: (7) ____

○ Geen van bovenstaande. Ik zou mijn ervaringen willen omschrijven als: (8)

____

Q4
<u>Brief over uw gewenste toekomst.</u>

Stel u voor dat u in een **tijdmachine** stapt en reist naar een door u **gewenste toekomst**. U kunt uit de tijdmachine stappen op één moment in de toekomst of op meerdere momenten.
Gebruik uw **verbeeldingskracht**: bedenk dat het gaat om iets wat nog niet gebeurd is en dat het een

kans is om te verzinnen wat er zou kunnen gaan gebeuren: stel u voor dat u de toekomst kunt ontwerpen!
Probeer met **zo veel mogelijk details** uw brief te schrijven, bijvoorbeeld over wat u belangrijk vindt op verschillende levensgebieden zoals wonen, werk, sociale relaties, of uw karakter of zelfbeeld. Schrijf wat er spontaan in u opkomt over de gewenste toekomst, probeer niet te veel na te denken. We zijn geïnteresseerd in uw eigen, persoonlijke ervaring.

U sluit de brief af met een **boodschap vanuit de toekomst** aan uzelf of aan anderen in de huidige tijd.

U heeft nu een globaal idee van de opdracht om een brief vanuit de toekomst te schrijven.
Hierna volgen stapsgewijs enkele vragen die u helpen om straks de brief te schrijven. Voel u vrij om vanuit deze suggesties de brief op uw eigen wijze te schrijven.

Het schrijven van een brief vanuit de toekomst duurt ongeveer **15 minuten** (sommige mensen hebben meer tijd nodig en anderen minder). Neem alle tijd die u nodig heeft voor het schrijven van een brief van **minimaal 1/2 A4**.

Q5
Wanneer speelt uw gewenste toekomst zich af? Hoe ver in de tijd reist u in de toekomst? Het tijdstip in de gewenste toekomst bepaalt u zelf. Dit kan 1 uur, dag, een week, of jaren later zijn. Misschien ziet u uzelf op een bepaalde leeftijd? Of in een bepaalde levensfase? Of waaraan merkt u dat uw gewenste toekomst zich op dat moment in de toekomst afspeelt?

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Q6 **Waar** bent u in de gewenste toekomst? Beschrijf hieronder bijvoorbeeld de **omgeving** of de **plek van uw dromen**, met zoveel mogelijk details die voor u belangrijk zijn. Of wat ziet of hoort u? Wat ruikt u? Of hoe voelt de toekomstige omgeving?

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Q7 Speelt de chronische aandoening een rol in uw leven in de gewenste toekomst? Op welke manier wel of niet? En welke rol? Op welke levensgebieden?

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Q8

Aan wie schrijft u de brief?

Bedenk aan wie u de brief wil schrijven: aan uw huidige ik of aan iemand anders (bijvoorbeeld uw kind of kleinkind, leeftijdgenoten, of de volgende generatie, etc.).
En hoe spreekt u deze persoon aan? (lieve, beste, geachte, etc.).

____

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Q9
U kunt nu de brief gaan schrijven. Het gaat dus om uw gewenste toekomst.

Stel u een gewenst toekomstig leven voor, waarin (met of ondanks uw chronische aandoening) een **wens, verandering of droom is uitgekomen**. Misschien heeft u iets bereikt wat u graag wilde. Of u leidt het leven zoals u dat wilt leven. Of u heeft een bepaald probleem opgelost. Of u heeft een goede manier gevonden om hiermee om te gaan.

Vertel uw verhaal over een concrete dag, of een specifiek moment, of een concrete gebeurtenis. Geef bijvoorbeeld details over **wie, wat, waar, of hoe** de gewenste toekomst eruit ziet of over **hoe u zich daarbij voelt**. Vertel bijvoorbeeld hoe u daar gekomen bent, of wat u heeft gedaan om dit te bereiken, of wat u achteraf het meest heeft geholpen, of hoe u op het leven van nu terugkijkt.

Met welke **bedoeling** schrijft u aan de ontvanger van deze brief? Of welke **boodschap** heeft u voor deze persoon?

____

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____

Q10 De volgende vragen van de vragenlijst (de Verkorte Dutch Mental Health Continuum) beschrijven gevoelens die mensen kunnen hebben. Lees iedere uitspraak zorgvuldig door en omcirkel het cijfer dat het best weergeeft HOE VAAK U DAT GEVOEL HAD GEDURENDE DE

AFGELOPEN MAAND.
In de afgelopen maand, hoe vaak had u het gevoel .....

	Nooit (1)	Eén of twee keer (2)	Ongeveer 1 keer per week (3)	2 of 3 keer per week (4)	Bijna elke dag (5)	Elke dag (6)
... dat u gelukkig was? (1)	○	○	○	○	○	○
... dat u geïnteresseerd was in het leven? (2)	○	○	○	○	○	○
... dat u tevreden was? (3)	○	○	○	○	○	○
... iets belangrijks hebt bijgedragen aan de samenleving? (4)	○	○	○	○	○	○
... dat u deel uitmaakte van een gemeenschap (zoals een sociale groep, uw buurt, uw stad)? (5)	○	○	○	○	○	○
... dat onze samenleving beter wordt voor mensen? (6)	○	○	○	○	○	○
... dat mensen in principe goed zijn? (7)	○	○	○	○	○	○
... dat u begrijpt hoe onze maatschappij werkt? (8)	○	○	○	○	○	○
... dat u de meeste aspecten van uw persoonlijkheid graag mocht? (9)	○	○	○	○	○	○
.... dat u goed kon omgaan met uw alledaagse verantwoordelijkheden? (10)	○	○	○	○	○	○
... dat u warme en vertrouwde relaties met anderen had? (11)	○	○	○	○	○	○
.. dat u werd uitgedaagd om te groeien of een beter mens te worden? (12)	○	○	○	○	○	○
... dat u zelfverzekerd uw eigen ideeën en meningen gedacht en geuit hebt? (13)	○	○	○	○	○	○

... dat uw leven een richting of zin heeft? (14)	○	○	○	○	○	○

Q11 De volgende vragen gaan over uw aandoening.

Mijn chronische aandoening is ...../ de belangrijkste diagnose die op mij van toepassing is, is:

____

____

____

____

____

Q12 Zijn er behalve deze diagnose nog andere diagnoses op u van toepassing?

☐ Nee, alleen deze diagnose is op mij van toepassing (1)

☐ Ja, namelijk: (2) ____

☐ Ja, en ook nog: (3) ____

☐ Wil ik niet zeggen (4)

Q13 Sinds wanneer heeft u de belangrijkste diagnose gekregen?

Vul hieronder het aantal in, van het aantal jaren geleden dat u die belangrijkste diagnose kreeg.

○ aantal jaren geleden: (1) ____

○ Anders, namelijk: (2) ____

○ Wil ik niet zeggen / weet ik niet (3)

Q14 Wat was uw leeftijd waarop u deze diagnose kreeg?

	Wil ik niet zeggen
	0 10 20 30 40 50 60 70 80 90 100
Ik kreeg de diagnose ongeveer op de leeftijd van .... ()	

Q15 Hoe heeft de chronische aandoening uw leven beïnvloed?

De chronische aandoening heeft mijn leven ...

○ **negatief** beïnvloed (1)

○ **positief** beïnvloed (2)

○ **zowel positief als negatief** beïnvloed (3)

○ **nauwelijks of helemaal niet** beïnvloed (4)

○ Anders, namelijk: (5) ____

○ Wil ik niet zeggen / weet ik niet (6)

Q16
De volgende vragen gaan over uw situatie op dit moment.

Wat is uw hoogst behaalde opleidingsniveau?

- ○ Lagere school (1)
- ○ Middelbare school (2)
- ○ MBO: Middelbaar Beroepsonderwijs (3)
- ○ HBO: Hoger Beroepsonderwijs (4)
- ○ Universiteit (5)
- ○ Anders, namelijk: (6) ____
- ○ Wil ik niet zeggen (7)

Q17
Wat is uw belangrijkste rol op dit moment?

- ☐ Ik studeer (1)
- ☐ Ik werk betaald (2)
- ☐ Ik doe vrijwilligerswerk (3)
- ☐ Ik heb op dit moment geen werk (4)
- ☐ Ik ben ziek of arbeidsongeschikt (5)
- ☐ Ik ben gepensioneerd (6)
- ☐ Anders, namelijk: (7) ____
- ☐ Wil ik niet zeggen (8)

Q18 De volgende vraag gaat over uw gewenste toekomst.

Wat is uw wens voor uw toekomst, qua opleiding of persoonlijke ontwikkeling?

☐ Ik wil een baan vinden (1)

☐ Ik wil vrijwilligerswerk gaan doen (2)

☐ Ik wil mijn opleiding afmaken (3)

☐ Ik wil starten met een (vervolg-)opleiding (4)

☐ Ik wil me op een andere manier ontwikkelen, namelijk: (5)
____

☐ ik wil iets anders veranderen, namelijk: (6)
____

☐ Ik heb geen wensen, ik ben tevreden met mijn situatie zoals die nu is (7)

☐ Anders, namelijk: (8) ____

☐ Wil ik niet zeggen / weet ik niet (9)

Q19 De volgende vragen gaan over algemene gegevens.

Wat is uw burgerlijke staat?

○ Ik ben ongehuwd (1)

○ Ik ben gehuwd of heb een geregistreerd partnerschap (2)

○ Ik ben gescheiden (3)

○ Ik ben weduwe / weduwnaar (4)

○ Anders, namelijk: (5) ____

○ Wil ik niet zeggen (6)

Q20 Wat is uw huidige woonsituatie?

- ○ Ik woon alleen (1)
- ○ Ik woon samen met mijn partner (2)
- ○ Ik woon samen met mijn partner en kind(-eren) (3)
- ○ Ik woon zonder partner met mijn kind(-eren) (4)
- ○ Ik woon samen met een of meer mensen met wie ik geen relatie heb (5)
- ○ Anders, namelijk: (6) ____
- ○ Wil ik niet zeggen (7)

Q21

Wat is uw leeftijd?

	Wil ik niet zeggen
	0 10 20 30 40 50 60 70 80 90 100
Mijn leeftijd (in jaren) is: ()	

Q22 Wat is uw geslacht?

- ○ man (1)
- ○ vrouw (2)
- ○ anders, namelijk: (3) ____
- ○ wil ik niet zeggen (4)

Appendix C

Table 1.

Codes and code descriptions per dimension of Futures Consciousness

Dimension	Code	Description
Time Perspective (TP)		
	Objective Time Horizon (OTH)	The writer has dated the letter (year, day) so that the exact timespan can be determined
	OTH-ST	ST short term: less than or 1 year ahead
	OTH-MT	MT midterm: over 1 year up to 10 years ahead
	OTH-LT	LT longterm: over 10 years or more ahead
	OTH - unspecified	The date has not been made explicit in the letter
	Subjective Time Horizon (STH)	The timespan can be deduced based on the depicted events in the letter
	STH Within Corona	During the Corona crisis period, typically describing social distancing measures or lockdown
	STH Extended Corona/ New pandemic normal	Aspects of Corona still influence life, even if the pandemic is already gone. It might be that certain measures (social distancing, wearing masks) or behaviour remains the same as during Corona.
	STH Relief of end of pandemic	A proximate post-corona future estimated or explicitly situated only weeks or months after the pandemic came to an end or when measures or the lockdown had ended.
	STH larger scope	A post-corona future situated clearly at a distance to the pandemic, with a focus on large (societal) changes
	STH timespan unclear	It is unclear when the depicted future takes place
Attribution of Agency (AA)		
	Degree of Agency	Section -level codes indicating (a) the degree to which the actor and action(s) are specified and clear and (b) the number of agency-aspects made explicit. There are four aspects of agency (actions, responsibility for actions, reflection on consequences of actions, intentions or plans for actions).

	Low Agency	There may be a specified agent, but the actions, responsibility, reflection on action consequences, and plans/intentions for action are vague.
	Intermediate Agency	There is an unspecified agent with 2 or more aspects of agency attributed, or there is a specified agent with one aspect of agency made specific.
	High Agency	There is a specified agent with 2 or more aspects of agency made specific.
	Distribution of agency	Letter-level code describing whether in the letter as a whole a collective or personal agent dominates
	Personal agency	In this letter agency is primarily allocated to a personal agent (typically an I-agent or You-agent, i.e., referring to the future or present self of the letter writer, sometimes including the immediate relations/family of the I).
	Collective agency	In this letter agency is primarily allocated to a collective agent, either the government, an organization, institution, community, or group.
	Mixed personal/collective agency	In this letter the allocated agency is equally distributed between collective and personal agents, for example because the letter has multiple sections which each have different actors varying between the personal life and societal developments.
Openness to alternatives (OA)		
	Attitude	Sentence-level code indicating the stance towards the future
	Closed	A closed stance towards what the future will hold, in giving a sense of certainty, predictability and control. This can be observed in word use (definitely, certainly, no doubt) and the lack of subjunctivizing language.
	Open	Openness towards what the future will hold, allowing uncertainty and unpredictability. Openness can be observed by content (I surmised, it seems, I doubt, as if) and by subjunctivizing language (Sools, 2012).
	Multiplicity	Letter-level codes for various ways in which multiple manifests in the letters in topics, thoughts or action possibilities
	Single-issue	Letters that predominantly deal with one central issue
	Multiple-issue	Letters dealing with at least 2 issues and a single key issue cannot easily be identified.

	Contrasting group action	Contrast is created in action possibilities between groups (some versus others, others and self, or different stakeholder groups).
	Reflective questions	Through raising reflective questions, the writer opens up multiple options and alternative perspectives
Awareness of Interconnectedness(AI)		
	Explicitness of systemic awareness	Section-level codes for letter parts showing the extent to which awareness of interconnectedness between system parts is demonstrated observably in implicit or explicit reflection.
	Implicit interconnectedness	The wording does not express a (cause and effect) relation between parts (e.g., generations, timeframes and/or domains). Parts are implicitly connected for example when a narrator moves from the description of developments at one level to developments in another, without referring to how one level influences the other.
	Explicit interconnectedness	A connection between levels, generations, times or domains is made explicit, for example by causal connectors or other linguistic markers or when the content of the letter reflects awareness of how things cohere, are part of a larger whole and cannot be thought of each other independently.
	Degree of Systemic awareness	Whole letter-level code of the degree of awareness shown overall of interconnectedness between parts, e.g. (a) personal-social-planetary levels; (b) generations; (c) times, e.g., past, present, future; (d) domains in life / society such as health, education, economy.
	No interconnectedness	One level only (no descriptions of explicit relations between levels)
	Some interconnectedness	Relations between 2 levels are mentioned explicitly (if other relations are mentioned implicitly, letters are coded at this level)
	Extensive interconnectedness	3 or more relations presented explicitly OR one relation is described in a way that shows complexity (e.g., nonlinear thinking) OR one relation is described extensively (= elaborative narrative)
Concern for Others (CO)		
	Kind of Concern	Section level code about the object of concern
	Self	Concern for the personal life of the writer (well-being, health, education, housing, etc.) and the immediate circle of friends and family

	Freedom	Concern about freedom of movement, of doing what one wants to do, of being free from fear
	Awareness of what matters	Realization or (renewed) appreciation of values in (personal) life
	Humans & generations	Concern for other humans beyond the immediate circle of friends and family (local or global) or even extending to generations before and after
	Society	Concern for social inequality, the economy, the health-care system, the educational system etc.
	Green	Concern for the environment, either locally (sustainable communities) or globally (e.g., climate change and transition to a green economy)
	Degree of Concern	Whole letter level code about the number of selftranscending concerns (from none to – nearly – all)
	Self-only	The writer shows concrete concern(s) related to the personal future (happiness, well-being, education, employment, finances) that may include the immediate circle of friends/family
	Low	One self-transcending concern is mentioned (e.g., freedom, awareness of what matters, humans/generations, society or green) with or without concern for self
	Intermediate	Two or three self-transcending concerns are mentioned (e.g., freedom, awareness of what matters, humans/generations, society or green) with or without concern for self
	High	Four or five self-transcending concerns are mentioned (e.g., freedom, awareness of what matters, humans/generations, society, green) with or without concern for self