Research Article

Younger Adults and the Coping of Chronic Disease - Community Health Nursing as A Flexible Approach to Care

Linda Iversen

1Department of Nursing and Management, Hamburg University of Applied Sciences, Hamburg, Germany

Correspondence to: Linda Iversen, MEd, Research Assistant, Department of Nursing and Management, Hamburg University of Applied Sciences, Berlin Gate 5, Hamburg 20099, Germany; Email: linda.iversen@haw-hamburg.de

Received: June 17, 2023 Revised: August 1, 2023 Accepted: August 14, 2013 Published: October 1, 2023

Abstract

Background: Dealing with chronic illness is a major challenge for patients. For younger adults, this means a major break in life but there are few suitable offers for this target group. Good integration of the disease into life is the starting point for well-being and quality of life. Community health nurses (CHNs) have the competency to help younger adults cope with their illness. Individualized care requires knowledge of what coping strategies the patient has established over a lifetime. Therefore, an analysis of the coping strategies of younger adults with chronic disease seems worthwhile.

Aim: This study aims to develop a care offer by a CHN that is specifically oriented towards the needs of people in health-disadvantaged neighborhoods and the associated difficult access to health care.

Methods: The narrative-biographical interview method was used to gain insight into the coping strategies of younger adults with chronic illness. Grounded theory methodology was used to analyze the interviews.

Results: A total of \( n=12 \) interviews were conducted with younger adults with a chronic or long-term illness. From these, six categories of coping strategies were identified. These are: (re)establishing the ability to act, illness as a focus in life, dealing with emotions, dealing with the outside and dealing with the inside, and the search for meaning.

Conclusion: The analysis of the different coping strategies provides the basis for care that fits the individual needs of young adult patients. The CHN concept responds flexibly to patients’ needs. Therefore, it can be assumed that it also responds individually to the forms of coping of the six categories. It can therefore be expected that CHN is suitable for the care of young adults with chronic diseases. There are numerous points of contact for the category that (re)establish the ability to act.

Keywords: young adults, chronic disease, coping, community health nursing

Citation: Iversen L. Younger Adults and the Coping of Chronic Disease - Community Health Nursing as A Flexible Approach to Care. J Mod Nurs Pract Res, 2023; 3(4): 23. DOI: 10.53964/jmnpr.2023023.
1 INTRODUCTION
The rising prevalence of long-term conditions is a global health problem. “Age”, for example, is considered a risk factor for acquiring chronic diseases, and the likelihood of becoming ill at an advanced age is increasing. The reasons why younger adults suffer from chronic diseases are complex. If we look at the prevalence of non-communicable diseases (NCDs), such as heart disease, diabetes, or cancer, according to the World Health Organization (WHO)’s 2022 report, they cost the lives of 17 million people under the age of 70 alone every year - the equivalent of one life every two seconds. NCDs are thus the cause of nearly three-quarters of all deaths worldwide[3]. In the same report it is outlined that risk factors should be addressed. In the United Nations 2030 Agenda for Sustainable Development, the political goal of reducing premature mortality from NCDs by one-third was agreed upon[2]. According to the WHO, there is little chance that this goal will be achieved[1].

The development of a chronic disease is often a life-changing event that has significant physiological, social, and psychological consequences[9]. In terms of primary and secondary prevention, care that intervenes early in the disease process can prevent disease development, reduce the risk of secondary diseases, and mitigate severe courses. The group of young adults with the disease is of particular interest here, as they still have a large part of their lives ahead of them - early integration of the disease into life and learning good coping strategies are starting points for well-being and quality of life. At the same time, they face special challenges. They are usually in a productive stage of life, trying things out, forming ideas about identity, life and the future. Central issues of middle adulthood represent, among others, identity in terms of personality development and professional development[4]. Dealing with chronic illness and, as a consequence, with multiple physical and psychosocial limitations is often difficult to integrate into this phase of life, as the accustomed lifestyle has to be abandoned. This is accompanied by a sense of lack of control and balance in life, to the point of experiencing a crisis[3]. Care services that specifically address the challenges faced by younger people with chronic illnesses are few and far between. Whereas in pediatrics, such as diabetes care, care is usually organized in an interprofessional, comprehensive, and child-centered manner, adult services expect their patients to be more independent and responsible for their own care[6]. However, young adults often participate in clinical assessments poorly or do not attend at all, which is associated with serious and costly medical consequences[7], such as negative long-term consequences for health status.

Structured patient education for chronic diseases, such as diabetes, is one of the essential treatment elements.

However, offerings from health care providers usually require time, resources, mobility and good German language skills, and the range of certified online providers is currently still limited[8]. Particularly in precarious, underserved districts, where people are often affected by many problems at once, there are few offerings that are geared to the patients’ living environments. Risk factors for chronic disease follow a social gradient: those who live socially disadvantaged lives have fewer resources to take care of their health[9]. Care that supports younger adults in the process of coping well with their illness understands the general conditions and social factors as influencing health and illness on the one hand but is also oriented toward their individual needs. An assessment of where the patient is in the coping process and what strategies he or she has acquired during life is of elementary importance.

CHN offers an approach to assessing needs of a specific target group and providing appropriate care services for them. Internationally, the CHN concept is already an integral part of primary care. In Germany, too, there are efforts to include CHN as a concept in primary care. As part of the Costa study, the CHN concept is currently being tested in Germany. The randomized-controlled trial, funded by the German Federal Ministry of Education and Research (BMBF), is investigating the use of community health nurses (CHNs) and changes achieved as a result with regard to factors such as disease management, health literacy and quality of life in patients with chronic diseases[10]. According to the WHO’ definition, CHNs combine nursing, public health, and social assistance and play a key role in health promotion, disease prevention, rehabilitation of illness and disability and improvement of the patient’s living conditions. CHNs work in a well-connected and interprofessional manner, enabling them to comprehensively manage complex cases. Anamnesis, assessment and identification of patient needs also fall within their task area[11]. An analysis of the life trajectories of younger chronically ill patients by a CHN seems worthwhile to understand as comprehensively as possible the various dimensions of experiencing and coping with the disease today and to find strategies for mastering the further course of life with the disease.

In theory and research, but also in practice, the topic of coping with illness is a widely discussed phenomenon across professions. Psychology offers many approaches and theories on the subject. One of the most frequently cited definitions of coping comes from the transactional stress model of Lazarus and Folkman[12] and describes coping as “constantly changing cognitive and behavioral efforts to manage specific external and / or internal demands that are appraised as taxing or exceeding the resource of the person”. There are a variety of theories of coping with illness, such as the four-phase model, which was developed specifically to address chronic...
and mental illness[19]. Differentiation of various coping styles or forms is also common, such as problem-focused, emotion-focused, or cognitive coping[12]. Various instruments have been developed to make the coping of chronically ill patients measurable. Often these have emerged in the course of qualitative research, and their categories and dimensions paint a picture of the various coping mechanisms. In German-speaking countries, the Freiburg Questionnaire for Disease Processing (FKV)[14] or the Trier Scales for Coping with Illness (TSK)[15] should be mentioned. As a result of a critical analysis of the questionnaires of the older generation, the Essen Coping Questionnaire (ECQ)[16] was developed, which is also used internationally. Further, the Brief COPE Inventory[17], for example, is used in the international area. Stress research also offers some instruments that are suitable for analyzing coping, such as the Stress Process Questionnaire (SVF)[18].

There is no uniform definition of the term “chronic disease”. As a rule, it refers to long-lasting illnesses that cannot be completely cured and result in a persistent or recurring increase in the use of services from the healthcare system[19]. The course dynamics are characteristic: stable phases alternate with crisis-like unstable phases[20]. There is a tendency for younger people to also suffer more frequently from these “classic” chronic diseases, which are often associated with an unhealthy lifestyle. However, it is reasonable to suspect that younger people also must contend with other long-term health problems than the older generation. In addition to the typical “lifestyle diseases” such as high blood pressure or diabetes, the present research showed that prevalence of other long-term health impairments such as endometriosis, chronic infectious diseases or epilepsy are also found here. In the following, all those long-term health impairments will be subsumed under the term “chronic disease” and only this term will be used.

1.1 Research Question and Objective

The categorizations of the questionnaires, whose constructions are often based on qualitative research, already allow conclusions to be drawn about coping strategies of chronically ill persons at a wide variety of levels. However, their dimensions and scales, as well as prior research, do not allow conclusions to be drawn about how specifically the group of younger chronically ill persons cope with their illnesses and leave unaddressed the question of how the various strategies relate to each other. An understanding of where learned strategies for dealing with health and illness originate can provide information about the current lifestyle of the young patients and, in the next step, offers starting points for changing health behavior today. This can result in fields of action for a Community Health Nursing in the counseling context. To develop a care offer by a CHN that is specifically oriented towards the needs of people in health-disadvantaged neighborhoods and the associated difficult access to health care, the following research question arises: What strategies do younger adults in a structurally disadvantaged quarter have in coping with their chronic disease(s)?

2 MATERIALS AND METHODS

2.1 Study Design

With the help of the method of the narrative-biographical interview and its techniques of the analysis insight into the life history of the younger chronically ill persons was taken. The conception according to Rosenthal[21] was applied, which is closely based on the instrument of the narrative interview originally developed by Schütze[22]. In the present work, the interview was pre-structured by naming the research context in advance and narrowing it down thematically to the focus on coping strategies. The three phases of the interview according to Rosenthal are: (1) the main biographical narrative, which initially gives patients the space to talk freely about their medical history, (2) narrative-internal follow-up questions, where the interviewer picks up on what has already been told in the main narrative, and finally (3) narrative-external follow-up questions, where specific topics are addressed that have not yet been mentioned, but which could be of interest from the interviewer’s point of view.

2.2 Data Collection

The interviews with younger chronically ill patients were conducted as part of the Costa study. The cooperation partner for the Costa study is the interprofessional, primary health center Poliklinik Veddel. It is in the Veddel district of Hamburg, which is exemplary for an underserved district of a major German city. A large proportion of residents receive transfer payments, and income per taxpayer is among the lowest in Hamburg[23,24]. Therapy services and specialists do not exist, and chronically ill people living here reach the outpatient care system comparatively late[25].

The interviews were conducted by a CHN. Some inclusion and exclusion criteria were defined to select suitable subjects. Included were people of working age (18-66 years) living in Veddel and medically cared for by Poliklinik Veddel with at least one chronic illness. For at least one of the chronic diseases, there is a medical diagnosis that is noted in the documentation program of the Poliklinik Veddel. Further chronic diseases could be subject of the interview if the patients self-reported them. Individuals who were in acute mental distress and / or unable to voluntarily consent to the interview for cognitive or psychological reasons were excluded. All interviews were documented by recording device. The data collection and analysis period were from April 2022 to March 2023.

2.3 Analysis

First, all conducted interviews were transcribed using the F4 transcription software. For further qualitative data and
text analysis, the software program MAXQDA was used. It was transcribed according to the method of Dresing and Pehl[26]. The methodology of Grounded Theory was used to evaluate the interviews. In terms of a circular research process and theoretical sampling, interviews were conducted and analyzed alternately until theoretical saturation was achieved. Analysis of the data involved the three-step coding process according to Strauss and Corbin[27]: open, axial, and selective coding. In open coding, each transcript was provided with concepts to summarize the content of each interview. In the next step, redundancies in the concepts were reduced and combined into categories. In the next step, axial coding, the coding paradigm[27] was used to facilitate systematic thinking about the research subject and to highlight where transitions and coping strategies could be identified in the transcripts. It distinguishes the central phenomenon (in this case, the chronic illness) underlying the transcript and its causal and contextual conditions, resulted action strategies (in this case, strategies for coping with the illness), which lead to consequences. To get closer to answering the research question, causal and contextual conditions as well as consequences were neglected in the further course. In the third step, selective coding, the coping strategies were summarized across transcripts into main categories and thus brought closer to theory building. The entire research process was accompanied by writing memos to fix initial hypotheses and theorizing about the research question and to incorporate them into the analyses[29].

2.4 Ethical Considerations

All study participants were informed verbally and in writing about the aims of the study. All patients who met the inclusion criteria signed the consent form. They were informed that they were free to withdraw from the study at any time and that the data collected and associated study results would be anonymized and would not be used for purposes other than the study. Each participant signed an informed consent form. The study was approved by the ethics committee of the institution to which the authors belong.

3 RESULTS

The results of the interviews, which lasted an hour on average, showed that the coping strategies are as varied as the clinical pictures of the young adults themselves. Coping is influenced by the severity of the disease and how much it affects everyday life, but also by how long ago the diagnosis was made and whether the onset of the disease was sudden or gradual. When dealing with an illness, it also plays a role whether the patient has the feeling that he or she can influence the course of the illness, but also whether he is infectious towards his fellow human beings due to the illness or whether he expects stigmatization due to the illness, as is often the case with depression. Finally, it is of great importance which determinants of health come into effect, for example, which material or social resources a patient has or does not have, and which can therefore have a supporting but also an inhibiting effect in coping with the disease.

One difference with patients who receive a diagnosis late in life is that younger adults who receive a life-altering diagnosis early in life learn early to cope with blows of fate. Several patients report having lost the youthful “sense of invincibility” that had prevailed until then when they received the diagnosis. However, this has not only disadvantages. One young patient describes that the chronic illness brought about a confrontation with loss and finitude, which enabled her to live consciously in the here and now. Another patient describes that her diagnosis enabled her to learn strategies at an early stage to deal with strokes of fate and that she feels better prepared for old age: “...that helps me to deal with things, and then maybe I already have my little suitcase or something. When things come later, that is” (Participant 3).

3.1 Sample Description

A total of 12 interviews were conducted with younger chronically ill patients until an approximate theoretical saturation was reached. The average age of the interviewees was 38 years. The youngest patient was 26 at the time of the interview, the oldest 57 years old. Five of the interviewees are female, six are male and one is non-binary. The interviewees have different nationalities: seven have the nationality German, two Macedonian, one Turkish, one Ghanaian and one German-Turkish. The numbers and types of chronic conditions varied among interviewees. Five of the patients had one chronic disease, four had two diseases, one interviewee had three diseases, and two patients had five or more diseases. The most common diseases were cardiovascular (hypertension, lymphedema, post thrombotic syndrome) and musculoskeletal (arthritis, rheumatoid arthritis, chronic back pain). Both affected six patients each. Five of the patients have nutritional and metabolic diseases (diabetes mellitus, obesity, hypothyroidism) and two patients have nervous system diseases (epilepsy, tension headache). Two of the patients suffer from mental and behavioral disorders (depression, sleep disorders). Other chronic diseases of the respondents (each one) include bronchial asthma, endometriosis, chronic hepatitis B, Crohn’s disease, iron deficiency anemia, post COVID-19. The diseases mentioned are in each case the chronic or recurrent form.

3.2 Coping Strategies

A total of six main categories were identified. These are (re)establishing the ability to act, illness as a focus in life, dealing with emotions, dealing with the outside, dealing with the inside and search for meaning. They are shown in Tables 1-6.

All the strategies identified for dealing with the illnesses
### Table 1. Category: (Re)establishing the Ability to Act

<table>
<thead>
<tr>
<th>Gaining Control</th>
<th>Losing Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acquiring knowledge</td>
<td>Overly involvement</td>
</tr>
<tr>
<td>Creating a fixed daily structure</td>
<td></td>
</tr>
<tr>
<td>Taking on responsibility</td>
<td></td>
</tr>
<tr>
<td>Creative processing</td>
<td></td>
</tr>
<tr>
<td>Make own decisions</td>
<td>Permanent weighing</td>
</tr>
<tr>
<td></td>
<td>Defiance</td>
</tr>
</tbody>
</table>

**Progression**

<table>
<thead>
<tr>
<th>Acceptance</th>
<th>Stagnation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health promoting behavior</td>
<td>Overcaution</td>
</tr>
<tr>
<td>Pragmatism</td>
<td>Fluctuating health behavior</td>
</tr>
</tbody>
</table>

### Table 2. Category: Illness as a Focus in Life

<table>
<thead>
<tr>
<th>Healthy Distance</th>
<th>Escape</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attitude change</td>
<td>Repression</td>
</tr>
<tr>
<td>Distraction</td>
<td>Addiction</td>
</tr>
<tr>
<td>Recovery</td>
<td>Hiding</td>
</tr>
<tr>
<td>Habituation</td>
<td>Self-deception</td>
</tr>
<tr>
<td></td>
<td>Trivializing</td>
</tr>
<tr>
<td></td>
<td>Deferring</td>
</tr>
</tbody>
</table>

**Self-care**

<table>
<thead>
<tr>
<th>Take care of oneself</th>
<th>Overcompensation</th>
</tr>
</thead>
<tbody>
<tr>
<td>indulge oneself</td>
<td>Become obsessed with the disease</td>
</tr>
<tr>
<td>Deceleration</td>
<td></td>
</tr>
<tr>
<td>Meditation</td>
<td></td>
</tr>
</tbody>
</table>

### Table 3. Category: Dealing with Emotions

<table>
<thead>
<tr>
<th>Processing</th>
<th>Destructivity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grieving</td>
<td>Depressiveness</td>
</tr>
<tr>
<td>Anger</td>
<td>Self-aggression and aggression towards others</td>
</tr>
<tr>
<td>Self-compassion</td>
<td>Self-pity / Resignation</td>
</tr>
<tr>
<td>Humor</td>
<td>Ridiculing</td>
</tr>
</tbody>
</table>

### Table 4. Category: Dealing with the Outside

<table>
<thead>
<tr>
<th>Draw Strength</th>
<th>Lose Strength</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extroversion</td>
<td>Searching for guilt outside</td>
</tr>
<tr>
<td>Own upgrading (compared to others)</td>
<td>Projection / Transference</td>
</tr>
<tr>
<td>Change of social environment</td>
<td>Social isolation</td>
</tr>
<tr>
<td></td>
<td>Conscious suppression (for performance pressure)</td>
</tr>
</tbody>
</table>

### Table 5. Category: Dealing with the Inside

<table>
<thead>
<tr>
<th>Adequate Self-reflection</th>
<th>Self-degradation / Isolation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Question own patterns</td>
<td>Ruminating</td>
</tr>
<tr>
<td></td>
<td>Introversion</td>
</tr>
<tr>
<td></td>
<td>Bottling up</td>
</tr>
<tr>
<td></td>
<td>Own blame</td>
</tr>
<tr>
<td></td>
<td>Self-sabotage</td>
</tr>
</tbody>
</table>

### Table 6. Category: Search for Meaning

<table>
<thead>
<tr>
<th>Taking Fate into One’s Own Hands</th>
<th>Resignation to Fate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Giving positive meaning to disease</td>
<td>Fatalism</td>
</tr>
<tr>
<td>Dealing with life and finiteness</td>
<td></td>
</tr>
<tr>
<td>Living consciously</td>
<td></td>
</tr>
<tr>
<td>Faith / spirituality</td>
<td></td>
</tr>
</tbody>
</table>
can be assigned to these main categories. During the evaluation, it became apparent that certain strategies have the same origin and, under certain conditions, can move either in one (more health-promoting) direction or in the other (more health-inhibiting) direction. For example, one interviewee described the grief associated with the loss of certain skills as a form of coping that she experienced as beneficial in the process of coping. However, if this grief takes over or stagnates, it can turn into depressiveness. Thus, it appears that one and the same circumstance is on a continuum with the two poles of “health-promoting coping” and “health-hindering coping”, and the subject’s coping can be located differently on the continuum depending on what stage of coping he or she is in, what the external circumstances are, and what resistance resources the person brings to the table.

The six main categories, along with the poles of their various coping strategies, are tabulated and contrasted below. The category of (re)establishing the ability to act seems to be of particular importance, since it plays a role - in different forms - in all interviews and particularly good points of contact for the CHN activity can be derived here.

3.3 (Re)establishing the Ability to Act

The most frequent strategies for dealing with the disease can be assigned to this category. All twelve patients experienced phases of discomfort up to and after diagnosis, with which they had to cope in everyday life. Regardless of the disease, patients experience some form of loss of abilities and freedom that they cannot control, such as loss of mobility, dependence on outside help or medication, or the need to avoid certain foods. The situation of having to live with the disease from now on often represents an elementary, sometimes crisis-like break in life, which often requires a complete reorganization of everyday life and the future. The struggle to gain or regain the ability to act is an elementary part of the coping process, which does not always succeed immediately and whose coping strategies move in areas of tension between gaining control and losing control, as well as between progression and stagnation.

Some patients can (re)gain control over their life situation by acquiring knowledge in a comprehensive way and thus become experts of their own disease. As one patient describes: “And then after a while I read how to deal with it, what to do about it. That you don’t have to put so much physical strain on yourself and stuff, what to look out for” (Participant 4).

Creating a fixed daily structure gives patients a sense of control over their life situation. A patient with severe hypertension who experienced loss of control in the form of hypertensive crises on several occasions reports how the same daily routine always gives her support and orientation: “Every day, before I go to bed, I check it. Every day. Yes, every day I check” (Participant 6).

One patient reports that especially in difficult, complaining phases, routine and a fixed daily structure is helpful to remain able to act: “Yes, further, so, the daily course as it must run, I have run, ne. Always the day” (Participant 4).

The conscious decision to take responsibility in dealing with the disease conveys the feeling of being able to exert a positive influence. For example, one patient with chronic hepatitis B reported how he behaved responsibly, especially toward those around him, for the purpose of protecting against infection: “Ehm and I have then over a few years really very disciplined Ehm, dealt with this issue so. So, was aware of my responsibility” (Participant 7).

Some patients resort to creative processing to cope with the illness, such as making music, art, or writing (“journaling”): “The thing I usually do is called a brain dump. That I set an alarm clock for myself for seven or ten minutes, for example, and I write down everything that comes into my head. (...) Exactly, just take time for me there” (Participant 11).

“...Yes, rather I think music on an emotional level so to USE. Or also to allow the negative feelings and to accept that they are allowed to be there” (Participant 2).

To gain control, however, these coping strategies can change into an excessive preoccupation with the disease, so that the patient can become overly, almost obsessively, involved. One endometriosis patient describes mentally obsessing over minor symptoms out of fear of renewed episodes as follows: ‘I give it too much energy that maybe it would come back too. (...) if I somehow think that too much, maybe I still have it, and if I have pain now, that can come from that or something’” (Participant 5).

During (re)establishing the ability to act, some patients report a process in which they emancipate themselves from common opinions such as those of the physician or professional literature and make their own therapeutic decisions. For example, the patient with endometriosis reports that - after reading a lot - she decided against her gynaecologist’s advice to go back on the contraceptive pill: “Because people are just know so super little about it. Um, and then I decided not to do it” (Participant 5).

These decisions are not always in favor of the course of the disease, but often in favor of quality of life and give patients back some of their freedom. “Yeah, so, I’m, I’m still vaporizing (laughs), with the e-cigarette, but Ehm, the nicotine content is relatively low and yeah (laughs). It’s still a guilty pleasure” (Participant 2).

However, this can result in a constant balancing process
between “what do I allow / prohibit myself”, which patients sometimes describe as very exhausting. This asthma patient describes the permanent weighing like that: “But it’s just fun for me and if I want to smoke drunk somehow and my inner voice says I shouldn’t do it (laughs), I’m annoyed by it” (Participant 3).

Nevertheless, making one’s own decisions can turn into defiance, resulting in decisions that are not good for the disease. One patient with Chron’s disease describes how he defied professional recommendations about diet and subsequently faced bad episodes of disease: “But (sighs) with me it was then often like that, I, so certain resistance was also there. Ehm, so, no, I accept that maybe not” (Participant 2).

In addition to the struggle for control, there is also an area of tension between progressive behavior and behavior that causes stagnation in the processing process. Progressive behavior presupposes an acceptance of the life situation with illness and the readiness to face it actively: “Because you have to live with it, you have to look at how you can deal with it” (Participant 4).

Some patients accept their situation to a certain extent but see themselves less as a self-effective subject capable of acting. They find themselves in a state of passive let happen in which they try to transmit all responsibility to their environment. The asthmatic patient, who received her diagnosis many years ago, describes knowledge about her own disease: “And there also that I have somehow so determined, I do not know so really much. Um about this asthma”. And further in relation to disease education, “And of course I’m an adult and I could ask about all that, but I just obviously didn’t” (Participant 3).

All interviewees report health promoting behavior that they have integrated into everyday life in order to positively influence the course of the disease. This can be seen, for example, in the form of a healthy diet, regular check-ups with the doctor, taking medication reliably, or exercise. One young epileptic tells how he worked hard to regain his mobility after surgery: “I could slowly get up like this at home. But I didn’t feel anything on the right side. And I said, I’ll do it on my own. I always went for a walk” (Participant 12).

Often, this involves pragmatic solutions to better cope with the challenges posed by everyday illness. For example, one interviewee shares how he adapted his personal hygiene to living with post-COVID symptoms: “So, I also took a shower sitting down and stuff then kind of. And ehm cut my hair too, for example” (Participant 11).

Sometimes, however, progressive manners such as health promoting behavior and pragmatism can turn into an overcaution, so that the patient dares little or goes to the doctor even for the smallest complaints, as this patient describes: “So, I imagined that the first years after the diagnosis, I really went off at the slightest abnormality. So, there I was very sensitized” (Participant 7).

Another patient reports strongly fluctuating health behavior. Short, very ambitious phases in which he intensively pursues health-promoting behavior are followed by phases of inconsistency in which he lapses back into unhealthy behavior. Thus, the continuity of healthy behavior cannot be maintained permanently. “That’s right, I quit smoking. Started again. (…) (laughs) I don’t know. I’m just in that kind of process of starting again, I think” (Participant 9).

Often, such short-term behavioral changes are a reaction to worsening of the condition, or at least the prospect of it, as in the case of this patient with Crohn’s disease: “When just told by the doctors, yes, we might have to put an artificial anus in you. And then, a world collapses and then you think so shit, I must, I must change everything completely somehow” (Participant 2).

4 DISCUSSION

In the interviews, patients showed coping strategies that ranged between the poles of “health-promoting” and “health-inhibiting”. This phenomenon is already known from coping research. As early as 1995, Heim distinguished between “favorable” and “unfavorable” coping strategies in a review of coping-based intervention strategies[29]. Other approaches followed, differentiating between adaptive and maladaptive strategies, such as Meyer’s in mental illness[30]. The present work has also elaborated how these different strategies can be related to each other. within their opposing poles, they are generally not to be considered as either / or. All shades of grey exist between these poles, and often behavioral strategies are very close to each other, intermingling or alternating, depending on the situation the patient is currently in. For example, a patient may repress his illness for a very long time, but suddenly become active in the course of a disease flare-up and acquire a great deal of knowledge about his illness. After recovery, he may then repress again. A patient who represses his or her disease requires completely different care than a patient who is actively seeking information on how to manage his or her disease. As different and dynamically changing as the coping strategies are, as flexible must also be the health care services that can be taken up with the patient. Community Health Nursing enables individual care offers tailored to the patient’s situation. However, illnesses cannot be managed without the active participation of the patient. Therefore, it is elementary to understand where the patient whom the CHN is caring for is currently in the process of coping with the disease - only then can adequate offers be
created that link to the patient’s already established coping strategies.

In the context of the present work, the different coping strategies of younger chronically ill patients were investigated. A total of twelve interviews were evaluated. A diverse spectrum of coping strategies emerged, which can be grouped into six main categories. The category of (re)establishing the ability to act seems to be of particular importance here, as it was - in different ways - a content component in all interviews. All patients report that struggling for autonomy, control, and self-efficacy appears to be important in the coping process. This is consistent with findings from recent research, for example, a 2021 study showed that patients with chronic illnesses or long-term health conditions find it difficult to control their illness and its associated effects. At the same time, the patient’s own self-efficacy and ability to influence the course of the disease is assessed as declining - the greater the restriction, the lower the belief in self-efficacy[30]. This offers a variety of starting points for CHN to support the patient in gaining control vs. losing control or progression vs. stagnation in the areas of tension and to land more in the spectrums that give (back) the patient’s ability to act and promote health. The prerequisite for this would be a comprehensive medical history at the beginning of care as well as a treatment concept designed for the long term, which creates trust between CHN and patient and provides opportunities for continuous exchange.

Where a patient is currently in these coping spectrums depends very much on whether the patient has disease insight. The interviews showed that most patients - and this is by no means always the moment of diagnosis - experience a “moment of awareness” at some point in the disease process, when they understand the full extent of the disease and its consequences on life, but also realize that they are the main actor in this process with the possibility of influence and decision-making ability. Two of the patients interviewed had not yet reached this moment of awareness at the time of the interview. Those interviewees who had reached this moment tended to find a better way of dealing with their illnesses, i.e., they were able to locate themselves in the more health-promoting areas in the fields of tension presented. The reasons that lead to this moment can be very different. Often an impulse from the outside is necessary for this. For example, one patient who was diagnosed with bronchial asthma in childhood reports that she did not fully understand her medical condition until the start of the COVID-19 Pandemic, when all chronically ill patients received the prescription for three free FFP2 masks in the mail[32]. Another patient reported depressive behavior after her diagnosis, which she was only able to change when she noticed behavioral abnormalities in her child and related them to her depressive behavior. A young epileptic experienced a long period of immobility and unsuccessful rehabilitation after brain surgery. Eventually, the family got him to take control of his destiny and to do walking training himself every day.

Some patients report a lack of professional and comprehensive education, so that they did not understand what their disease meant for a long time. In some cases, this may be due to repression. However, many patients also report that they would have liked to have received better information in order to cope successfully with their illness and that they have had bad experiences with health care professionals in the course of their medical history, including misinformation from professional staff in the care context, which not only made the process of coping more difficult, but in some cases even hindered it. For example, one patient with chronic hepatitis B reported that he had unnecessarily isolated himself from his environment for a year because his doctor did not inform him that his viral load had been below the detection limit for a long time, despite regular checks. Other patients report that good education and knowledge of trusted, reliable contacts in the health care system, such as primary care physicians or CHNs, are supportive in coping with illness.

Observing that patients demonstrate better disease management after this moment of awareness can be an important connecting point for CHNs, especially because an external stimulus can be helpful in this process. Knowing the patient’s acquired coping patterns, the CHN can be an impetus in this process, for example, by providing education, mirroring the patterns, and showing alternative ways of coping. Whether counseling is accepted depends on whether it reaches the patient at the stage where they are currently in their coping process. But also, whether it considers factors such as the patient’s level of knowledge and his language, whether an interpreting service can be involved. The choice of meeting location and descriptive training materials are also important. International studies show that creating individualized care plans, process evaluation, and always readjusting interventions, as well as supporting the patient in developing their own solution strategies and empowerment are core activities of CHNs[33]. Also, research shows that CHNs have the required competencies to support patients in their coping, especially in (re) establishing the ability to act. Promoting patients’ self-determination, supporting them in their self-management, and deriving individual measures, among other things, are identified as competencies of CHNs[34].

Research into coping strategies always focuses on the individual health behavior of a patient, i.e., in the sense of behavioral prevention, it starts with the individual in order to consider - in this case health-promoting or
health-risking - coping behavior[35]. However, in order to positively influence the coping process in the long term, the general conditions, socio-spatial and social circumstances must also be considered as factors influencing the health and illness of a patient. Only when relationship prevention and behavioral prevention are thought of together are strategies for (disease) prevention effective and sustainable[36]. The interviews also show that external influencing factors directly affect the process of coping with the disease. Experiences of discrimination are an example, which are described in different ways in the interviews by people with migration history. For example, one person of color describes her experience of racism, which is expressed in the form of pressure to perform at work. According to the patient, the pressure to perform better in order to receive equal recognition as white people is a phenomenon that most people with a migration history are familiar with. For example, it can lead to active suppression of chronic illness and people returning to work too early to avoid prolonged sick leave. And put up with consequential or long-term damage to do so. The suppression of illness due to performance pressure can also be seen in some male patients. Due to internalized, toxic ideas about masculinity, they do not disclose the actual extent of their illness at work or in their social environment, or they conceal it altogether. In addition to the above-mentioned, many other external factors play a role in dealing with the disease, such as the financial situation, housing situation or stress due to work or study. The aspect of relationship prevention could not be dealt with in this study. However, it is essential to include these factors in care as well, and they can be the basis for further research to develop care practices for the target group of younger chronic illness patients.

The question arises as to what extent the coping strategies of younger chronically ill people differ from those of other target groups, such as the chronically ill in general or older chronically ill people. It must be questioned whether it may be possible to draw on stress research and whether the strategies that young people use in dealing with their illness can be equated with forms of stress management in general. Here, it is worth taking another look at the previously mentioned scales of the questionnaires that are used in the German area in research on the topic of coping with illness as well as coping with stress. In the SVF, for example, the use of pharmaceuticals is a category to query possible substance abuse. But it would be better to ask about the use of other means, such as alcohol or drug use, as a coping strategy as well. Some questionnaires lack an intercultural component that also reflects lifestyle characteristics of migrants. The questionnaires show a lot of overlaps with the results of this study, although some of them use different terms. Examples are rumination, search for social integration, threat defense and search for information and exchange of experience (TSK)[37]. Also, in parts, a distinction is made between health-promoting or health-inhibiting strategies, such as in the FKV[14] and ECQ[16] (“depressive processing” vs. “problem-oriented coping”). The twenty scales of the Stress Processing Questionnaire (SVF)[38] reflect diverse categories that were also evaluated during the interviews of the present work. However, some categories of the questionnaires do not seem to be sufficiently differentiated to reflect the results of the interviews. For example, in the SVF, the use of pharmaceuticals is a category to query substance abuse, but it would be better also to query the use of other substances, such as alcohol or drug use as a coping strategy, during this. Some questionnaires lack an intercultural component that also reflects the lifestyle characteristics of migrants. Furthermore, self-compassion as distinct from self-pity should be mentioned. The latter is mentioned in the SVF and ECQ, but this is rather assigned to depressive processing and can have a resigned character. Self-compassion, on the other hand, was identified in the interviews conducted as a component conducive to the processing process. Nevertheless, different poles in aggression need to be opened. It can be helpful and relieving in coping to give room to the emotion of anger as long as no one is harmed. If it turns into self-aggression or aggression towards others, it can have harmful effects on health. The mentioned questionnaires do not distinguish these types of aggression. Some categories are apparently not found in any of the mentioned questionnaires. Examples include creative processing, spirituality (as a complement to faith), giving positive meaning to disease and the continuum between humor and ridiculing. This may indicate that these are specific strategies used by younger chronic disease patients and can be incorporated into CHN care to improve patient self-efficacy. Social isolation is mentioned in the few interviews, but it does not play a major role. When it did play a role, interviewees cited depressiveness as the predominant cause. For the elderly, the cause of social isolation could be more related to functional limitations or immobility due to chronic illnesses and lower quality of life. According to a 2011 study, chronic illness, physical functional limitations, chronic pain, and social isolation, among others, are the most important risk factors for suicide in older age[37].

5 CONCLUSION
The analysis of the different coping strategies provides the basis for care that fits the individual needs of the patient. As different as the coping strategies are, the care services that link to them must also be flexible. CHNs can respond flexibly to patients’ needs and have the skills required to support younger adults with chronic illness in their coping. Therefore, it is likely that it can individually address the coping styles of the six categories, making it suitable for the care of young adults with chronic illness.
In particular, it is important to include those strategies in the care that younger patients with chronic diseases show. Further research is needed to determine the extent to which the results of the present work can be translated into an assessment to make results practically applicable in the care of young chronically ill adults.

Acknowledgements
I would like to thank Poliklinik Veddel for the cooperation.

Conflicts of Interest
The author declared no conflict of interest.

Author Contribution
Iversen L was responsible for data collection and analysis, manuscript writing.

Abbreviation List
BMBF, Federal Ministry of Education and Research (Germany)
CHNs, Community health nurses
ECQ, Essen Coping Questionnaire
FKV, Freiburg Questionnaire for Disease Processing
NCD, Non-communicable diseases
SVF, Stress Process Questionnaire
TSK, Trier Scales for Coping with Illness
WHO, World Health Organization

References
[16] Franke GH, Jagla-Franke M. Essen Coping Questionnaire [In German]. ZPID: Trier, Germany, 2021. [DOI]
[22] Schütze F. The technique of narrative interviewing in interaction field studies illustrated by a project investigating communal power structures, 2nd ed. Bielefeld University, Faculty of Sociology, 1978.
[27] Strauss A, Corbin JM. Basics of qualitative social research [In German]. Beltz: Weinheim, Germany, 1996.
[28] Przyborski A, Wohlrab-Sahr M. Qualitative Social Research:
A Workbook, 5th ed [In German]. De Gruyter Oldenbourg: Berlin, Germany, 2014. [DOI]


[31] Stiftung Gesundheitswissen. Health orientation and information behaviour of the chronically ill. Secondary analysis in cooperation with the Institute for Demoscopy Allensbach [In German]. Accessed 23 April 2022. Available at: [Web]


[33] Iversen L, Wolf-Ostermann K, Petersen-Ewert C. What are the responsibilities of a community health nurse [In German]? Prävention Gesundheitsförderung, 2022; 18: 299-307. [DOI]

[34] Lidauer H, Kainrath S, Schule E et al. Skills and competencies of community health nurses [In German]. Pflegewissenschaft, 2022.

