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Disempowerment Among Adults With Chronic Illness: A Concept Analysis Using the Walker and Avant Method

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ABSTRACT

Aim: To clarify the concept of disempowerment in adults with chronic illness.

Design: The Walker and Avant approach to concept analysis was used.

Methods: A systematic literature search was performed on 14 February 2024, using the following databases: CINAHL, PubMed, PsycINFO, Sociological Abstracts and ProQuest Dissertations & Theses Global A&I: The Humanities and Social Sciences Collection. Studies examining adults' experience of individual disempowerment stemming from chronic illness were included. Definitions and descriptions of the concept in the included studies were extracted and synthesised into defining attributes, antecedents, and consequences.

Results: Forty-five articles were included. Two defining attributes were identified: (1) diminishing opportunities to take control and (2) clients' dissatisfaction with diminishing control. Antecedents were changes in health status related to chronic illness and expectation mismatch within the client, or between clients and their care partners. The consequence of disempowerment was disengagement in the context of disempowerment.

Conclusions: Disempowerment was found as the state of dissatisfaction with diminishing opportunities to control personal lives, which stems from changes in health status and expectation mismatch and leads to disengagement in the context of disempowerment. Contrary to prior studies, where disempowerment was often considered an outcome of an imbalanced relationship between clients and care partners, the present findings showcased disempowerment as a holistic illness experience, involving changes in health status. The understanding of disempowerment as the dissatisfaction with the situation of diminishing opportunities to take control differentiates this concept from the opposite of empowerment, which is conceptualised as clients' ability to make decisions or manage diseases. Findings further highlight the importance of understanding clients' illness experience comprehensively and providing care in a manner that is matched with clients' abilities, expectations and needs. It is suggested that operationalising the concept based on this understanding is necessary in order to understand correlations between disempowerment, its causes and consequences.

Impact: Disempowerment has been applied to describe interruptions in their states of being, perceived role performances, and independence in adults with chronic illness from diverse perspectives in the extant literature, such as the opposite of empowerment, action to take away control over personal lives and a state of diminishing ability to tackle problems. Through clarifying the concept, this article will guide the communication, measurement tool development and response in clinical practice.

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Summary

- In the context of chronic illness, disempowerment is a concept which might require healthcare professionals' more comprehensive understanding of clients' illness experience and care in a manner that is matched with clients' abilities, expectations and needs.
- Further research about disempowerment in adults with chronic illness might be required, focusing on the operationalisation of the concept to further understand its correlation, causes and consequences.

1 | Background

Disempowerment is often used to describe the experiences of adults with chronic illness, but the understanding of this concept remains unclear and lacks consensus. The word *disempower* has been defined as taking away someone's confidence and their sense of being in control of their life (Cambridge University Press, n.d.). Another definition of *disempower* is to deprive of power, authority, or influence, making weak, ineffectual or unimportant (Merriam-Webster, n.d.). Although both definitions show a shift in power and control, one refers solely to an action taken, whereas the latter also emphasises the negative influence or outcomes of such an action. In healthcare disciplines, the understanding of disempowerment generally relates to the experience of losing power to control personal lives. This is particularly relevant to older adults with chronic illness, as they typically experience a loss in their intrinsic capacities, such as locomotor capacity and cognition, and their functional abilities (e.g., decision-making) (World Health Organization 2021). This decline might be associated with illness experiences that diminish their sense of control and independence (World Health Organization 2021), or a lack of control over treatment regimens and disturbed personal lives (De Silva et al. 2021). Several studies have also linked this experience to the uncertainty brought about by chronic illnesses and the treatments (De Silva et al. 2021), the well-intended help or supervision provided by families or healthcare professionals after diagnosis (Low et al. 2018), and healthcare practice based on the biomedical model, which focuses on the diseases rather than the person or the meaning of their illness experience (Gaylord 1999; Kitwood 1990). Faulkner (2001b) suggested that disempowerment can worsen clients' health outcomes, such as provoking doubts about functional performance and depressive symptoms.

Previous research has generally conceptualised disempowerment as the absence of empowerment (Gibson 1991; Hartford et al. 2019), but emerging research suggest disempowerment is an independent phenomenon that can simultaneously occur with empowerment, and that the two are not mutually exclusive. For example, Waycott et al. (2016, 10) described their technology-based social intervention as both 'empowering and disempowering', as it effectively enhanced self-expression among the participants but also amplified withdrawers' existing illness experiences. Similarly, some practices which are considered as empowering, such as giving information for disease management, might arouse participants' perception of

'disrupting their sense of inner control' when they receive too much information than felt necessary (Small 2012, 248). These examples highlight disempowerment and empowerment can co-occur. Although several concept analyses conducted on empowerment among adults with chronic illness define empowerment as a process to enhance clients' abilities to manage their condition and feelings of control (Dowling et al. 2011; Fotoukian et al. 2014; Small 2012), the co-occurrence of empowerment and disempowerment might imply that disempowerment cannot be simply understood as an absence or the opposite of empowerment.

In the context of older adults with chronic illness, Kitwood (1990, 182) defines disempowerment as actions taken for the client 'even though he or she is able to do them, albeit clumsily or slowly.' Faulkner (2001b, 18) interprets this concept in the context of the care of older adults in hospitals as 'events undoubtedly unpleasant for clients to experience, for many they also represent uncontrollable circumstances'. Kilian et al. (2003, 1138) view this concept as treatments without positive effects on the ability to confront mental illness, which evokes the perception that their attempts to manage their illness are 'meaningless'. Therefore, disempowerment might be perceived as an action to take away control over personal lives, regardless of clients' ability, or a state of diminishing ability to handle health-related problems. Although a common theme of losing control over personal lives might be found, these definitions illustrate various understandings of the concept of disempowerment. Specifically, disempowerment might or might not necessarily occur within a power dynamic between clients and care partners as the illness experience or treatments alone can provoke a sense of disempowerment.

The essence of disempowerment has not been clearly established given the understandings and applications of this concept vary widely in the extant literature, such as the opposite of empowerment (Gibson 1991; Hartford et al. 2019), action to take away control over personal lives (Kitwood 1990) and a state of diminishing ability to tackle problems (Faulkner 2001b; Kilian et al. 2003). If disempowerment is understood solely as the opposite of empowerment, the oversimplification might result in care practices that fail to address the needs of individuals experiencing disempowerment (Salmon and Hall 2004). It is also important to clarify whether disempowerment can occur beyond a power dynamic between clients and care partners so that the needs of individuals experiencing disempowerment can be comprehensively captured. Clarification of this concept might be needed for retrieval, analysis and utilisation of information which captures the essence of this phenomenon. A definitive understanding of disempowerment will guide its communication, measurement and response in clinical practice, ensuring clients with chronic illness can relieve disempowerment or build buffers for preventing future disempowerment.

The aim of this concept analysis is to clarify the concept of disempowerment in adults with chronic illness. Three research questions are: (a) What are the defining attributes of disempowerment experienced by adults with chronic illness? (b) What are the antecedents related to chronic illness that contribute to disempowerment among the clients? (c) What are the consequences of disempowerment among the clients?

2 | Methods

2.1 | Approach

The Walker and Avant approach to concept analysis was used in this concept analysis because it focuses on the subtle nuances of the concept, refining the defining attributes to the fewest number that help differentiate the concept from related concepts (Gunawan et al. 2023; Walker and Avant 2019; Watson 1991). The varied meanings of disempowerment might not necessarily be time-dependent, so Rodger's evolutionary method, which focuses on transitory use instead of the subtle nuances of the concept, might not be suitable. The Walker and Avant approach consists of eight steps: (1) select a concept; (2) determine the aims or purposes of the analysis; (3) identify all uses of the concept; (4) determine the defining attributes; (5) identify a model case; (6) identify additional cases: borderline, related, and contrary cases; (7) identify antecedents and consequences and (8) define empirical referents (Walker and Avant 2019). This concept analysis was reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist (Page et al. 2021) (Data S1).

In this concept analysis, disempowerment was identified as the concept to study, which completed Step 1. Step 2, which is to determine the aims or purposes of the analysis, was fulfilled by the aim of this study to clarify the concept of disempowerment in people with chronic illness.

2.2 | Data Sources

Step 3 is suggested identifying as many uses of the concept as researchers can find via dictionaries, thesauruses and available literature (Walker and Avant 2019). Dictionaries, health-related electronic databases and reference lists of included studies were searched. Dictionaries, health-related electronic databases and reference lists of included studies were searched. Five health-related databases were employed, namely Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, PsycINFO, Sociological Abstracts and ProQuest Dissertations and Theses Global. The search strategy combined keywords and Medical Subject Headings (MeSH) using Boolean operators, developed based on the research question. Keywords for the concept domain included disempower* and (dis)empower*. Keywords for the context domain included chronic disease, heart disease, cancer and other types of chronic diseases. No specific restrictions (such as timeframe or study design) were set during the database search to ensure that the search captured as many eligible studies as possible. However, only studies written in English were included in this review. Details of the search strategies are provided in Data S2. The search was conducted in February 2024.

2.3 | Eligibility Criteria

Any study designs with qualitative, quantitative or mixed-method approaches, reviews, book chapters, theses and editorials were eligible for inclusion in this analysis. The PICO (Population, Interest and Context) framework was utilised to devise the eligibility criteria for this concept analysis.

2.3.1 | Population

Studies examining adults with chronic illness were included, irrespective of whose perspectives, such as those from the clients and/or their care partner (i.e., family members or healthcare professionals).

2.3.2 | Interest

Studies defining and describing disempowerment at the individual level were included.

2.3.3 | Context

Studies examining the experience stemming from chronic illness were included. However, studies examining the experience stemming from any context other than chronic illness, such as feminism and racial discrimination, were not included.

2.4 | Selection Process

Retrieved studies were imported into EndNote 20 (The EndNote Team 2024) and duplicates were removed by EndNote, followed by manual screening. The title and abstracts were screened against the eligibility criteria, as mentioned above, followed by full-text screening.

2.5 | Data Extraction

All words and phrases which define or describe disempowerment, with instances elaborating the concept in the included studies were recorded for subsequent steps 4–8.

2.6 | Data Analysis

Words and phrases which were used repeatedly to define or describe the concept, the causes and the consequences were noted. The terms were subsequently collapsed into themes. The themes were grouped into defining attributes, antecedents or consequences (Steps 4 and 7). The defining attributes, antecedents and consequences were tested with actual and composite cases for clarification and validation. Instances similar or related to the concept were identified and retained to help delineate borderline and related cases. Findings were discussed among the research team to minimise the bias from individual knowledge and culture in the analysis.

3 | Results

3.1 | Search Results and Study Characteristics

In total, 728 articles were identified from the electronic databases. 173 duplicates were removed by Endnote, followed by a manual check. Ineligible studies were those with interests not related to disempowerment or context not related to chronic

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources

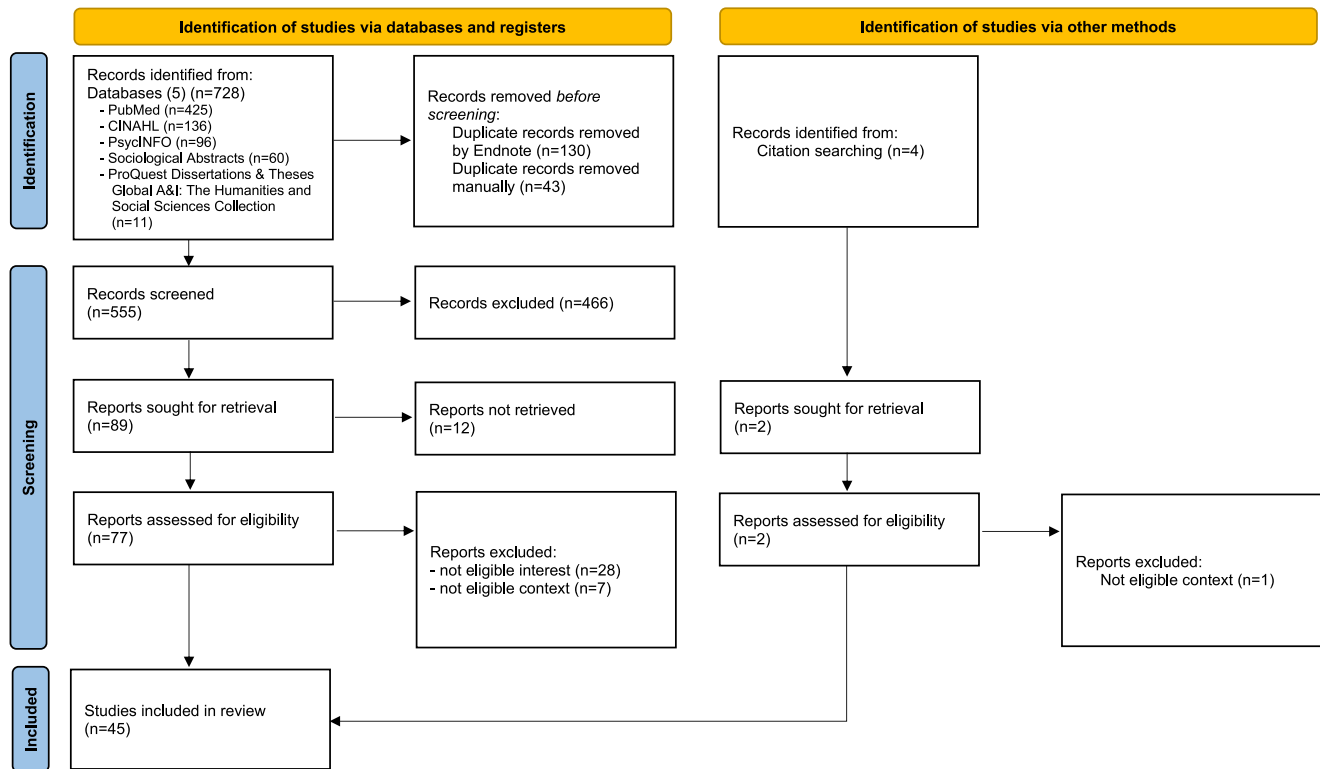


FIGURE 1 | The Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) flowchart of the selection process.

illness. The full text of 77 articles was screened and 42 articles were considered eligible. After adding two eligible articles identified from the reference lists of included studies (Goldsmith 1996; Kilian et al. 2003), 45 articles in total were included in this concept analysis. See Figure 1 for details.

The characteristics, definitions and descriptions of disempowerment of the included studies are reported in Data S3. The included articles were published from 1990 to 2024. There are 29 qualitative studies, six systematic reviews of qualitative studies, two mixed-method studies, two discussion papers, one book chapter, one literature review, one reflective essay, one recommendation essay, one scoping review and one theoretical paper, mainly aiming to explore the experience of chronic illnesses and related healthcare services. Disempowerment is most frequently mentioned as the theme of the book chapter or results in the included articles. The term is also used as a descriptor in the introduction, results and discussion in some articles.

To facilitate the understanding of the concept of disempowerment among adults with chronic illness, the defining attributes, antecedents and consequences are illustrated in Figure 2.

3.2 | Defining Attributes

Defining attributes are the characteristics of a concept with the most frequent mentions with the concept and the use to

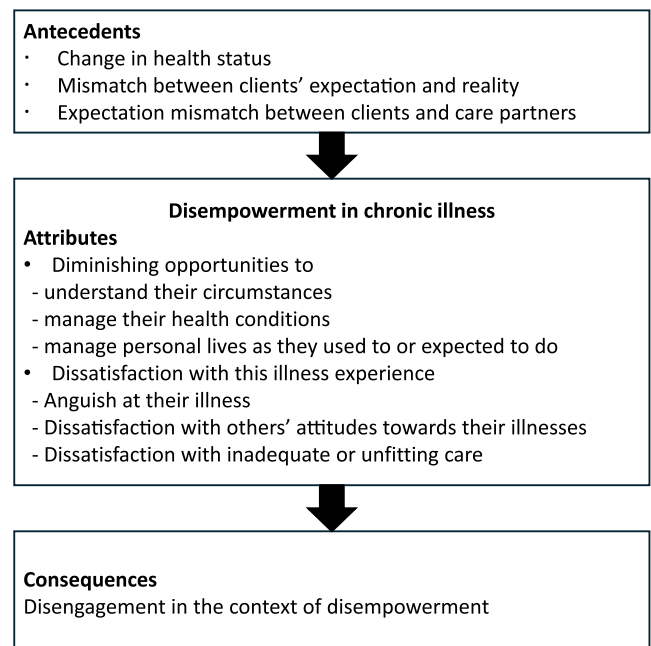


FIGURE 2 | The defining attributes, antecedents and consequences of disempowerment among adults with chronic illness.

differentiate the concept from a similar or related concept (Walker and Avant 2019). Definitions and descriptions of the concept of disempowerment in included studies established six thematic categories and ultimately two defining attributes

(Figure 3). Disempowerment is a state in which an individual's opportunities to make choices over his or her own life diminish, and it dissatisfies the individual.

Diminishing opportunities to make choices over their own lives surface in relation to three themes: (1) losing opportunities to understand their circumstances; (2) losing opportunities to manage their health conditions and (3) losing opportunities to control personal lives as they used to or expected.

The first theme about losing opportunities to understand their circumstances emerges from clients' expression of being left 'in the dark about their condition' (Kim et al. 2023, 12). Difficulty in accessing illness-related information, such as test results, aetiologies and prognoses, was found, associated with the experience of disempowerment (Butler et al. 2021; Kim et al. 2023; Luker et al. 2015; Raj et al. 2019). Studies also showed that some of them, especially those with cognitive impairment, were not informed of their diagnoses and medical advice, even though their family members might have been informed (Low et al. 2018; Prato et al. 2019). Even though the information was provided, adults with chronic illness might find it difficult to process and remember it. Some clients indicated that they were confused about the explanations of reasons for their illnesses

(Caeiro et al. 2022; Leder 2018) and the treatment goals which were discussed with healthcare professionals (Rosewilliam et al. 2016; Turner 2012).

The second theme, which is the most frequently mentioned in included articles, is the inability to manage their health conditions. The theme is supported by studies pinpointing their difficulty in engaging in decision-making about their care with inadequate information, discussions and treatment options (Beresford et al. 2023; Caeiro et al. 2022; Collins et al. 2017; Hamilton et al. 2022; Hartford et al. 2020; Hersh 2015; Lawn et al. 2014; Raj et al. 2019; Rosewilliam et al. 2016; Sirch et al. 2017; Sumpton et al. 2020; Wilkinson 2001). Some studies also showed that participants might be passive in actions about their care (Berry et al. 2020; De Silva et al. 2021; Duke 2006; Kim et al. 2023; Kirkland 2003; Lawn et al. 2014; MacNeela et al. 2015; Mitchell et al. 2020). Moreover, patients' experience of disempowerment is also associated with difficulty in articulating their concerns and needs, communicating with health professionals and collaborating with them (Caeiro et al. 2022; Eassey et al. 2019; Feddersen et al. 2022; Hartford et al. 2019; Hersh 2015; Walker and Avant 2019). They also experienced their will being neglected or overridden (Goldsmith 1996; Kitwood 1990; MacKinlay 2002).

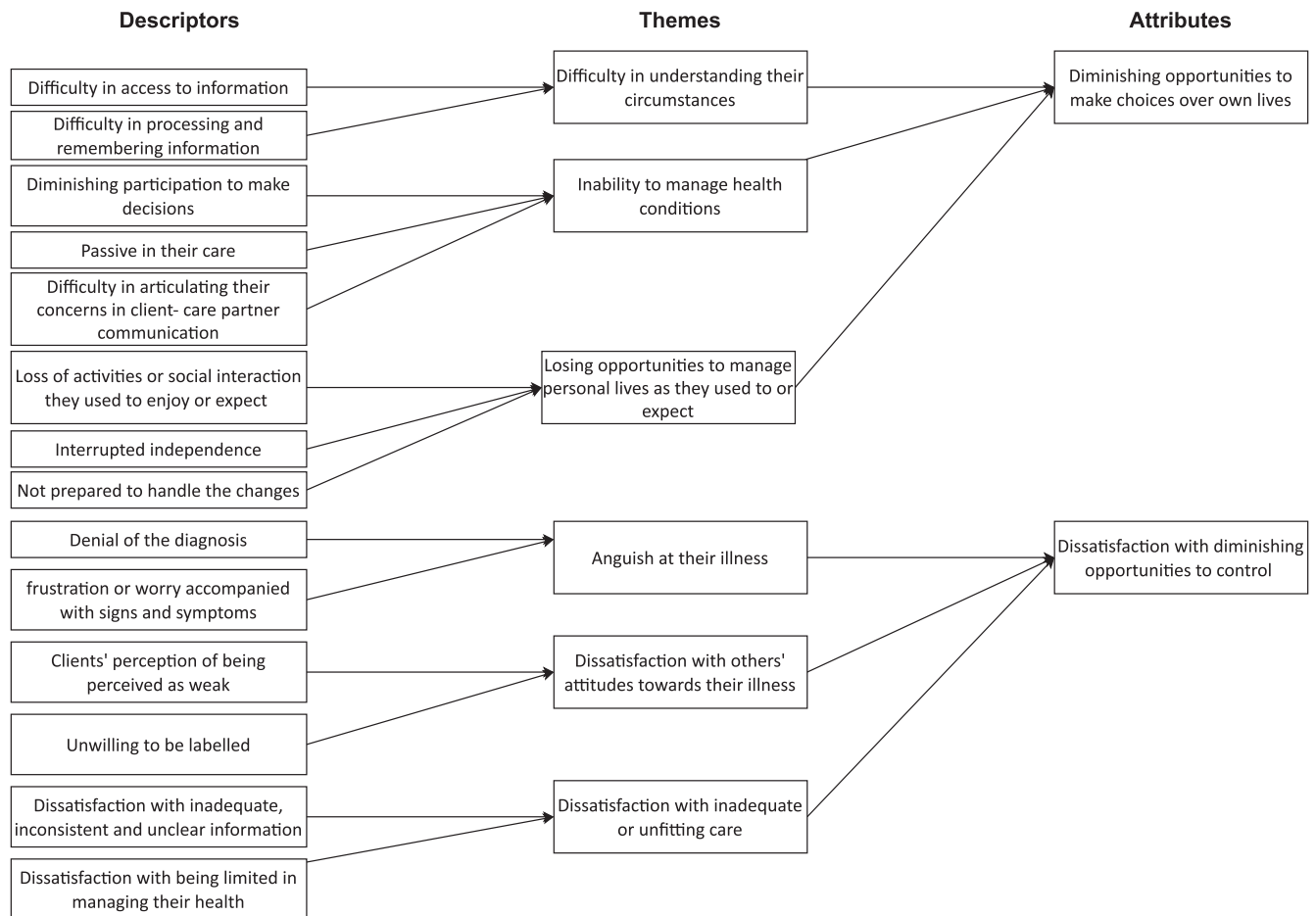


FIGURE 3 | Flowchart between the descriptors, themes and attributes.

The third theme relates to losing opportunities to manage personal lives as they used to or expected to do so before. The experience of disempowerment is not only related to diminishing opportunities to understand or manage health conditions but also to the change in their personal lives. Studies revealed that the disempowering experience arose from reduced activities and social interactions, which they used to enjoy or expected to do, after suffering symptoms or complications of chronic illnesses (Bruns et al. 2019; Eassey et al. 2019; Holopainen et al. 2018; Leder 2018; MacNeela et al. 2015). Their independence was interrupted (Mitchell et al. 2020; Turner 2012). When adults with chronic illness had not prepared themselves (Sumpton et al. 2020) or equipped themselves to handle the change in lives (Hartford et al. 2019; Low et al. 2018; Luker et al. 2015; Probst et al. 2021; Rees 2018; Schmoll 2011; Sixsmith et al. 2014), the feeling of disempowerment appeared.

Another attribute is dissatisfaction with the state of diminishing opportunities to control health conditions and personal lives, which distinguishes the notion of disempowerment. This attribute recurs in included studies with three themes: (1) anguish at their illnesses; (2) dissatisfaction with others' attitudes towards their illnesses and (3) dissatisfaction with inadequate or unfitting care.

The first theme is the emotional response to their illnesses, tending to manifest as anguish. Adults with chronic illness, such as cancer, dementia or low back pain, might initially deny their illness and its diagnosis as they might realise these conditions might become part of their self-identity and persistently affect their lives (Chang et al. 2004; Low et al. 2018; MacNeela et al. 2015). They might also have negative emotions, such as desperation, frustration or worry when clients suffer the signs and symptoms (Berry et al. 2020; Hamilton et al. 2022; Kim et al. 2023; Luker et al. 2015).

The second theme highlights their dissatisfaction towards how others perceive them and their illness. Studies revealed that individuals with chronic illnesses might often be perceived by healthcare professionals and family members as delicate, ignorant and passive persons (Alsawy et al. 2020; Bruns et al. 2019; Duke 2006; Eassey et al. 2019; Hartford et al. 2019; Holopainen et al. 2018; Low et al. 2018; Lundell et al. 2020; MacNeela et al. 2015; Rees 2018; Sixsmith et al. 2014). The clients expressed their reluctance to be labelled in such ways and felt dissatisfied by these perceptions (Chang et al. 2004; Duke 2006; Feddersen et al. 2022; Prato et al. 2019; Turner 2012).

The third theme which emerges from clients' perception of care is their recognition of care being inadequate or unfitting. Clients with chronic illness indicated dissatisfaction with inadequate, inconsistent and unclear information they received (Beresford et al. 2023; Holopainen et al. 2018; Kim et al. 2023; Lundell et al. 2020; Wilkinson 2001). The theme is also supported by some studies showing the clients' responses to a diminished ability to manage their health conditions. Some participants felt anxious, dissatisfied and frustrated by being restricted from decision-making and actions of their care (Butler et al. 2021; Collins et al. 2017; De Silva et al. 2021; Hersh 2015; Hung and Chaudhury 2011; Sumpton et al. 2020). Facing some services which they found difficult to access or unsuitable,

some interviewees also expressed annoyance or dissatisfaction (Feddersen et al. 2022; Hartford et al. 2019; McDougall et al. 1997; Raj et al. 2019; Sirch et al. 2017).

3.3 | Antecedents

The antecedents of disempowerment are the conditions or actions that are compulsory before the onset of this state (Walker and Avant 2019). They include changes in health status related to chronic illness, mismatch between clients' expectation and reality as well as expectation mismatch between the clients and their care partners, which limit their opportunities to engage in the decision-making process or managing personal lives.

Disempowerment occurs in the context of chronic illnesses when individuals encounter symptoms, complications, and illness uncertainty, affecting their health status. Symptoms, such as pain, might hinder the clients from living as they had expected, triggering their dissatisfaction with the condition (Bruns et al. 2019; Holopainen et al. 2018; Leder 2018; MacNeela et al. 2015). One interviewee with chronic pain stated that:

I'm not even asking for the pain to totally go away, I'm asking for it to get to a point where I feel once again active in all parts of my life especially in particular writing and being out in the country, in the mountains, in the wilderness areas, that's been like a huge part of my life and it's been taken away.

(Bruns et al. 2019, 722)

Enduring symptoms might strip clients of their expected lives, potentially leaving them dissatisfied with diminishing opportunities to make choices over their own lives. A sense of disempowerment might also be generated when deteriorating intrinsic capacity, due to the complications of chronic illnesses or side effects of treatments, make it difficult for clients to decide own health management plan and to maintain independence (Luker et al. 2015; MacKinlay 2002; Sirch et al. 2017; Turner 2012; Wilkinson 2001). Moreover, studies highlighted the impact of uncertainty over chronic illness's development on clients' ability to plan their care, their perception of their illness and their feeling of disempowerment (Beresford et al. 2023; Chang et al. 2004; Holopainen et al. 2018; Rosewilliam et al. 2016).

Mismatch between clients' expectation and reality is also critical to the occurrence of disempowerment. Among adults with chronic illness, this mismatch was found when they found they were actually less likely than anticipated to express their concerns (Hersh 2015) and their conditions deteriorated more significantly than expected (Probst et al. 2021). These experiences might provoke their feeling of dissatisfaction with diminishing control. Moreover, dissatisfaction often stems from the mismatch between what patients expected and what care they actually received. This is frequently attributed to inadequate or unfitting care they received (Beresford et al. 2023; Butler et al. 2021; Hersh 2015; Holopainen et al. 2018; Probst et al. 2021; Rosewilliam et al. 2016; Turner 2012).

Beyond the intrapersonal factors, the expectation mismatch between clients and their care partners might also trigger the feeling of disempowerment. Chronic illness might alter roles and relationships within clients' families. Some studies indicated that the sick role, disfavoured by clients, might be emphasised by family members (Alsawy et al. 2020; Chang et al. 2004; Low et al. 2018; Rees 2018). For example, some participants living with dementia might feel inferior when their care partners impose a particular standard in their interactions, which seemingly reinforces their unwanted sick role (Alsawy et al. 2020). Patients with chronic illness found that care partners, especially family members, might underestimate patients' abilities (Bruns et al. 2019; Low et al. 2018), disregard their will to maintain independence to some extent (Alsawy et al. 2020; Raj et al. 2019) and provide 'well-intentioned' support or monitoring (Low et al. 2018, 825). This might inhibit patients from managing their health conditions and controlling their personal lives as they used to or expected. With care partners' expectations imposed on them, adults with chronic illness might also struggle to communicate with them (Rees 2018; Turner 2012). An unsolved expectation mismatch between clients and their care partners might spark the feeling of dissatisfaction with losing control. Moreover, chronic illness might create a relationship between clients and healthcare professionals, forming expectations for each other. Some clients might believe that healthcare professionals clearly understood their diseases' causes, prognoses and management strategies and helped them understand their circumstances (Caeiro et al. 2022; Chang et al. 2004; Rosewilliam et al. 2016). However, their expectations were not met when healthcare professionals provided inconsistent information (Holopainen et al. 2018; Kim et al. 2023; Sumpton et al. 2020), used jargon which clients find difficult to understand (Beresford et al. 2023; Caeiro et al. 2022; Kim et al. 2023; Leder 2018; Prato et al. 2019; Rosewilliam et al. 2016), disclosed diagnoses to family members instead of patients (Low et al. 2018; Mitchell et al. 2020) and refused to listen to clients' concerns (Chang et al. 2004; Hartford et al. 2020; Hung and Chaudhury 2011; Lawn et al. 2014; Lundell et al. 2020; Sirch et al. 2017). These behaviours might result from healthcare professionals' expectation of clients as being incapable of making decisions (Duke 2006; Goldsmith 1996; MacKinlay 2002) and their expectation of themselves as being authoritative in this relationship (Eassey et al. 2019; Hamilton et al. 2022; Luker et al. 2015; Raj et al. 2019; Sixsmith et al. 2014; Walker and Avant 2019). However, clients might not accept these expectations, leading to a feeling of disempowerment (Eassey et al. 2019; Raj et al. 2019).

3.4 | Consequences

Consequences are events or incidents that occur as a result of the occurrence of the concept (Walker and Avant 2019). Disempowerment results in clients' disengagement in the context of disempowerment, manifesting in three aspects: self-care, relationships with care partners and healthcare services in use.

In terms of self-care, Low et al. (2018) suggested that the feeling of disempowerment in people with dementia caused by relatives' underestimation of their abilities potentially leads to doubts over their self-care abilities even though they were still capable, or even the conflict between clients and care partners. One of the

examples in Low et al. (2018, 19) stated that the participant told his family member not to 'reprimand' him as he could not tolerate the situation which they kept correcting him.

In terms of relationships with care partners, individuals might distance themselves from care partners. Attempts to isolate themselves from family members or friends were found in some studies after participants felt dissatisfied with care partners' misunderstandings of their circumstances and their imposition of limitations for clients to maintain independence (Alsawy et al. 2020; Bruns et al. 2019; MacNeela et al. 2015). Fading therapeutic relationships were also shown in some studies stating that patients reduced trust and interactions with healthcare professionals (Caeiro et al. 2022; Eassey et al. 2019; Goldsmith 1996; Hartford et al. 2020; Lawn et al. 2014; Lundell et al. 2020).

Moreover, in terms of healthcare services in use, dissatisfaction with inadequate or unfitting care might lead to doubts or even refusal of care or medical advice from the services (Eassey et al. 2019; Hung and Chaudhury 2011; Lundell et al. 2020; Prato et al. 2019; Turner 2012). Some clients might find alternatives to reduce disempowerment, such as finding other clinicians (Hartford et al. 2020).

Although disengagement in the context of disempowerment might serve as the coping response to disempowerment, this process might become maladaptive, mediated by the perceived abilities and availability of resources to relieve disempowerment. Low et al. (2018) suggested that the feeling of disempowerment in people with dementia might alter their way of viewing their self-care abilities, potentially leading to overdependence on care partners regardless of their abilities or symptoms. Overdependence on care partners (Caeiro et al. 2022; Lawn et al. 2014; Low et al. 2018) and a loss of a sense of personhood (Goldsmith 1996; Leder 2018; Schmoll 2011) might therefore be manifested. Also, without sufficient resources to disengage from the context of disempowerment, some clients might surrender to finding solutions and feel powerless (Holopainen et al. 2018; Hung and Chaudhury 2011; Turner 2012).

3.5 | Model Case

The model case of disempowerment, which demonstrates all the defining attributes (Walker and Avant 2019), is adopted from one of the eligible articles (Low et al. 2018).

A person living with early-stage dementia experienced a difficult time with a sense of losing control as the symptoms of dementia affected his day-to-day living. He said 'I was slowing down, losing my train of thought. I couldn't do things as well as I used to'.

He was not explicitly given the diagnosis of Alzheimer's disease, though his family had been told. He thought this implied healthcare professionals and the family considered that he needed to be "protected" or could no longer make decisions. Besides, he was

disappointed in less information provided than expected, so he was unwilling to talk with them about his condition and thoughts.

He received well-intended help or supervision provided by carers with underestimation of his abilities or dementia symptoms after diagnosis. He felt annoyed with their “best for you” thought. He thought he was disempowered.

This case embodies the defining attributes of disempowerment. His opportunities to understand his condition and to make choices over his own life diminish, and he feels dissatisfied with the situation. The antecedents are also reflected in this case: the symptoms of dementia, the difference between his own expectation of life with the illness and reality as well as expectation mismatch with his family and healthcare professionals, which diminish his opportunities to make informed choices over his own life, provoking his dissatisfaction. As a consequence, he became reluctant to interact with his care partners.

3.6 | Borderline Case

The following borderline case, which consists of some defining attributes (Walker and Avant 2019), is adapted from another eligible article (Kirkland 2003).

A person living with type 2 diabetes prefers experts to make decisions about diabetes management for him, whatever it was his desire or not, because he thought healthcare professionals were already familiar with his condition and their decisions were best for him.

This shows the client voluntarily diminishes his opportunities to make decisions without a perception of dissatisfaction, potentially because he received expected care.

3.7 | Contrary Case

This is the constructed contrary case showing the absence of disempowerment.

A breast cancer patient was provided with sufficient information about her condition, treatment options and prognoses. She felt satisfied with adequate support for her to autonomously make the decision.

This case does not show any defining attributes of disempowerment. Her ability to manage her health condition is sustained with satisfactory healthcare support.

3.8 | Related Cases

Related cases are concepts closely linked to the concept to be analysed but without all the defining attributes (Walker and Avant 2019).

Learned helplessness is one of the related cases, used interchangeably with disempowerment in some studies (De Silva et al. 2021; Goldsmith 1996; Low et al. 2018). Lubinski describes the condition of disempowerment among nursing home residents with dementia as learned helplessness, which occurs when things happen regardless of their responses, resulting in the thought that any further action is futile (Lubinski, 1991, as cited in Goldsmith 1996). However, in contrast to the earlier understanding of helplessness as a learned belief that further action is futile, Maier and Seligman (2016) have re-examined the concept of helplessness, suggesting that helplessness is the default response to prolonged adverse events. Helplessness seems different from disempowerment, whether it is taught or inborn, as the latter, involving the state of dissatisfaction, potentially triggers further action to avoid unpleasant stimuli, such as switching clinicians (Hartford et al. 2020).

Another related case is powerlessness, mentioned in Goldsmith (1996). Powerlessness is defined as the ‘lived experience of lack of control over a situation, including a perception that one’s actions do not significantly affect a result’ (Herdman and Kamitsuru 2014). It is also different from disempowerment, as the state of dissatisfaction potentially triggering further action before helpless or hopeless thoughts emerge.

Disempowerment might be perceived as the state prior to helplessness and powerlessness. Recognising disempowerment might prevent maladaptive outcomes from client disengagement in the context of disempowerment, such as helplessness or powerlessness.

3.9 | Empirical Referents

Empirical referents might help measure the existence of the concept (Walker and Avant 2019). However, no quantitative studies or instruments to measure disempowerment among adults with chronic illness were found in this search. Another search, which used keywords for the study design, such as questionnaire* and scale*, and did not include keywords for the context domain (chronic illness), was conducted via the same databases. Two instruments were identified to measure disempowering interactions between patients and healthcare staff in the hospital (Coyle and Williams 2001; Faulkner 2001a). The survey of person-centredness in secondary care includes three disempowering behaviours, such as ignoring clients’ thoughts about treatments, omitting to hear their questions and treating them like children (Coyle and Williams 2001). Another scale to measure empowerment and disempowerment is also related to interactions between healthcare professionals and older adults admitted to hospital, which the disempowerment subscale comprises hampering patient collaboration in care planning, dominating in care planning and being apathetic about clients’ needs (Faulkner 2001a). Both scales seemingly centre on the behaviours exhibiting that clients’ control over their health management during hospitalisation is weakened by healthcare professionals. However, the items might not cover the full spectrum of client-staff interactions which diminish clients’ opportunity to make choices over their own lives, and the two scales seem to overlook clients’ perception of diminishing control and aspects other than client-staff interactions. The limitations of

the two instruments might inhibit recognising the problem of disempowerment, the state of dissatisfaction with diminishing opportunities to make choices over own lives, in settings other than hospital.

4 | Discussion

To our knowledge, this is the first concept analysis of disempowerment in adults with chronic illness. Disempowerment was found as the state of dissatisfaction with diminishing opportunities to make choices over personal lives. Although the opportunities to control his or her personal life were acknowledged to partly relate to the predominant understanding of empowerment, dissatisfaction with diminishing control might differentiate disempowerment from the opposite of empowerment. Disempowerment was also examined as a holistic illness experience, contrary to the predominant focus on the imbalanced relationship between clients and their care partners.

4.1 | Disempowerment as Holistic Illness Experience

Disempowerment was not only relevant in managing health conditions and building relationships with healthcare professionals but also in other aspects of chronic illness experience, such as overcoming the changes in lives and interrupted independence. Faulkner (2001b) and Kitwood (1990) defined disempowerment in the context of interactions between healthcare professionals and clients living in hospital or residential facilities, whilst Kilian et al. (2003) explored this concept in the context of managing mental illness. Our findings support their understanding of disempowerment among adults with chronic illness, which disempowerment is associated with diminishing opportunities to make decisions and implement actions about their own care. However, disempowerment is not limited to the context of interactions between clients and healthcare professionals or services. It also appeared in other aspects of chronic illness experience, particularly overcoming the changes in personal lives and interrupted independence. The existing literature also provided an understanding that disempowerment stems from the experience of chronic illness with a mismatch between clients' expectation and reality, not restricted to the imbalanced power relationship between clients and their care partners.

4.2 | Disempowerment Not Solely the Opposite of Empowerment

The understanding of disempowerment as the state of dissatisfaction with diminishing control might differentiate this concept from the opposite of empowerment and explain how disempowerment and empowerment can simultaneously co-exist. Patient empowerment is predominantly understood by most healthcare professionals as a process or capacity to increase clients' compliance or adherence to care recommendations (Anderson and Funnell 2010). This perception was criticised for viewing the root of the problem at clients' behaviour instead of the approach

to care, which ignores clients' dissatisfaction with their care (Anderson and Funnell 2010; Funnell et al. 1991). Consistent with the literature, this study found that the feeling of disempowerment is generated when clients might not accept some healthcare professionals' expectations of them as being incapable of making decisions. Anderson and Funnell (2010) asserted that patient empowerment should be a process to increase the capacity of patients to think critically and make autonomous, informed decisions and an outcome as a result of the process. An updated definition of patient empowerment in the context of chronic diseases by a review of concepts and measures of patient empowerment was also conceptualised as an outcome of patients' capacity for self-control, disease management and decision-making (Cerezo et al. 2016). A comparison of our findings with this definition might confirm that one of the defining attributes of disempowerment (i.e., diminishing opportunities to control his or her personal life) might make this concept partly related to the predominant understanding of the absence of empowerment. However, the feeling of dissatisfaction might be veiled by the positivity of the concept of empowerment which seemingly sounds encouraging to improve clients' capacity. Salmon and Hall (2004, 54) commented some interventions were 'professionally regarded as empowering' by giving clients opportunities to manage their health conditions but actually disempowering by blocking healthcare professionals from understanding clients' expectations and needs, and thereby dissatisfying clients with expectation mismatch and losing opportunities to take control of their health conditions as they expected. Our concept analysis might unveil the important attribute (i.e., the feeling of dissatisfaction with diminishing control) of disempowerment, differentiating this concept from the opposite of empowerment, which is conceptualised as patients' capacity to make decisions and maintain independence. Regardless of the capacity to make choices over personal lives and maintain independence, clients with chronic illness might experience diminishing opportunities to make choices and feel dissatisfied with the situation. If disempowerment is understood solely as the opposite of empowerment, care practices might fail to address the needs of individuals experiencing disempowerment.

4.3 | Implications

The identification of defining attributes of the concept of disempowerment might hold significant implications for clinical practice and research. Disempowerment is a multidimensional concept, considering the opportunity to control personal lives and the feeling of dissatisfaction with illness experience. Recognising this concept might help healthcare professionals conduct a comprehensive assessment and provide holistic care, such as identifying disempowered aspects and corresponding risk factors, developing appropriate attitudes towards clients and providing physical resources, social support and care in a manner which is matched with patients' abilities, expectations and needs.

Differentiating disempowerment from the absence of empowerment might also arouse healthcare professionals' attention to their responsibility to understand clients' expectations and needs and value interactions with patients in chronic illness management. Understanding disempowerment as a distinct construct

might also assist researchers in considering a wider perspective, including empowering and disempowering aspects of possible strategies, when they design interventions for adults with chronic illness. Furthermore, the boundaries of disempowerment might be indicated by this study, potentially differentiating this concept from related concepts, such as powerlessness, and forming the basis for operationalising this concept to understand correlations between disempowerment, its causes and consequences and to evaluate corresponding interventions.

4.4 | Limitations

Although the search strategy, using the terms disempower* and (dis)empower* as keywords, was confirmed to be appropriate and the included studies were conducted in Western and non-Western countries, we could not eliminate the slim possibility that different languages and cultures might influence the analysis of the concept when non-English articles are not included.

5 | Conclusion

Disempowerment was found to be the state of dissatisfaction with diminishing opportunities to control personal lives. Contrary to prior studies, where disempowerment was often considered an outcome of an imbalanced relationship between clients and care partners, the present findings showcased disempowerment as a holistic illness experience. The understanding of disempowerment as the dissatisfaction with the situation of diminishing opportunities to take control differentiates this concept from the opposite of empowerment, which is conceptualised as clients' ability to make decisions or manage diseases. Findings further highlight the importance of understanding clients' illness experience comprehensively and providing care in a manner that is matched with clients' abilities, expectations, and needs. It is suggested operationalising the concept based on this initial understanding in order to understand correlations between disempowerment, its causes and consequences.

Author Contributions

H.Y.J.T., D.S.K.C., G.W.K.H.: Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; H.Y.J.T., D.S.K.C., E.A.C., G.W.K.H.: Involved in drafting the manuscript or revising it critically for important intellectual content; H.Y.J.T., D.S.K.C., E.A.C., G.W.K.H.: Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content; H.Y.J.T., D.S.K.C., E.A.C., G.W.K.H.: Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that supports the findings of this study are available in the [Supporting Information](#) of this article.

Peer Review

The peer review history for this article is available at <https://www.webofscience.com/api/gateway/wos/peer-review/10.1111/jan.70057>.

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