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ARTICLE

Understanding wellbeing from the perspective of youth with chronic conditions: A group concept mapping approach

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Abstract: Promoting wellbeing for youth is a global health priority and young people with chronic conditions demonstrate disproportionately low wellbeing compared to their peers. However, wellbeing is variably defined, and little is understood as to what wellbeing means for this population. The aim of this study was to develop a conceptualisation of wellbeing that is rooted in the perspectives of young people with chronic conditions. Group concept mapping, a structured, mixed method, and participatory based technique, was conducted with 11 participants aged 16-25 with various health conditions. Youth advisors were involved from the initial planning of the research to the final interpretation of the data. In a series of focus groups, participants generated statements that encapsulated their sense of wellbeing. From the generated ideas, a refined list of 62 statements was finalised in consultation with a youth advisory group. Participants then individually sorted the 62 statements into groups that made sense to them; individual data were combined, then analysed using multidimensional scaling to create a visual map of the ideas. Hierarchical cluster analysis was used to group the mapped ideas into clusters, resulting in seven 'domains' of wellbeing: (1) 'Embodying authentic self'; (2) 'Being a young person'; (3) 'Abilities and capacities'; (4) 'Self-understanding and nurturing'; (5) 'Hopeful future outlook'; (6) 'Supportive systems and communities'; and (7) 'Emotional support and validation'. These findings demonstrate the importance of considering inter-personal, intra-personal, and systemic factors in understanding wellbeing for youth with chronic conditions. The high level of participation throughout the research process allowed us to develop a concept of wellbeing that is nuanced and highly specific to this unique group. Implications for measurement, intervention and healthcare delivery for youth with chronic conditions are discussed.

Keywords: chronic conditions, wellbeing, youth, mixed methods, group concept mapping

1. Introduction

Understanding and promoting wellbeing for youth is increasingly a global health priority for research, policy, and practice (Mei et al., 2020). Of particular importance is understanding wellbeing for vulnerable groups - such as young people with chronic health conditions - who are more likely to experience low wellbeing and mental health challenges (Alderman et al., 2019; Banati & Bacalso, 2021). The umbrella term 'chronic condition' encapsulates a wide variety of ongoing physical health diagnoses that require medical intervention and impact an individual's daily functioning, with examples including chronic pain, asthma, cancer, dysautonomia, and Myalgic Encephalomyelitis/chronic fatigue syndrome (Bernell & Howard, 2016). Research has

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demonstrated increasing prevalence of chronic conditions in younger populations, with several studies estimating up to 30% of youth may be affected (Ferro et al., 2015; Virk et al., 2024).

While managing a chronic condition may have a significant impact on an individual at any stage of the lifespan, this experience can be especially challenging for young people. Between the ages of 16 and 25, young people undergo significant neurological, biological and psychosocial changes, all while being faced with a complex array of developmental tasks such as identity development, cultivating peer relationships, deciding plans for the future, and engaging with school and work tasks (Wood et al., 2018). Young people living with a chronic condition face additional demands such as following treatment schedules, managing unpredictable symptoms and coping with acute health complications, which often conflicts with their ability to engage with the standard challenges of development (Venning et al., 2008). This balancing act is hypothesised to be a key driver of the low wellbeing often demonstrated in young people with chronic conditions (Ferro et al., 2015).

Research has typically demonstrated that young people with chronic conditions score disproportionately low on wellbeing measures when compared to their peers (Denny et al., 2014; Helseth et al., 2016; Lynch Milder et al., 2023). However, the impact of chronic conditions on young people's wellbeing is complex and can vary depending on the specific condition characteristics as well as various demographic and socio-economic factors (Savage, 2014). Our evolving understanding of wellbeing in this population is also contingent on the appropriateness of the instruments for assessment of wellbeing in the context of youth chronic conditions. It is likely that for young people with chronic conditions, general wellbeing definitions do not comprehensively capture the unique interplay of health and developmental factors that ultimately shape wellbeing (Flannery et al., 2017). Furthermore, general models may position physical health as a key tenet of wellbeing, which fails to recognise how wellbeing can manifest for a young person despite ill physical health (Carel, 2007). Given the lack of consensus on how youth wellbeing, and wellbeing more broadly, should be defined, discrepancies in scores on wellbeing measures between young people with and without chronic conditions may in fact be reflective of differences in the ways that those with chronic conditions *experience* wellbeing.

1.1 Challenges in defining wellbeing

While there is general alignment on the importance of wellbeing across different stages of the lifespan, no consensus has been reached on how wellbeing, or positive mental health more broadly, should be conceptualised and measured (Iasiello et al., 2024). Across theoretical approaches, there appears to be general agreement that wellbeing is a holistic, multi-faceted construct, although the wellbeing dimensions specified by each approach differ widely (for an overview, see Dodge et al., 2012). This lack of a unifying framework has been met with consistent criticism from researchers extending back over three decades, with Ryff stating in 1989 that “the task of defining the essential features of psychological wellbeing” has been neglected “at the most fundamental level” (p. 1069). More recently, the multitude of varying definitions and models of wellbeing has been argued to ‘dilute the construct’ (Tov, 2018, p. 1), and has led to the development of disparate assessment tools, each measuring wellbeing via distinct constructs, such as overall life appraisals, presence of positive emotions, or external indicators such as financial security (Iasiello et al., 2024) .

Broadly, theoretical approaches to conceptualising wellbeing can be divided into hedonic and eudaimonic perspectives. Eudaimonic approaches conceptualise wellbeing as becoming one’s ‘true’ self, living in a way that aligns with personal values and allows an individual to cultivate a life worth living (Lambert et al., 2015). An early use of the eudaimonic approach is Ryff’s (1989) conceptualisation of wellbeing which is comprised of six dimensions, autonomy, self-acceptance, positive relationships with others, environmental mastery, purpose in life, and personal growth. In contrast, the hedonic approach is concerned with positive emotional states and the relative lack of negative emotional states, as well as an individual's subjective cognitive evaluations of their life satisfaction (Tov, 2018). An early example of this approach is subjective wellbeing as described by Diener (1984), who criticised the eudaimonic perspective for the use of an external 'value framework' (p. 543) over subjective judgements in defining wellbeing. In addition, more recent conceptualisations of wellbeing often take a 'hybrid approach', combining both hedonic and eudaimonic perspectives as well as potentially incorporating ideas from various paradigms (Lambert et al., 2015). Examples of hybrid models of wellbeing include the hybrid PERMA model (See Seligman, 2011) and Wong's (2010) model of existential positive psychology. However, these models have been created to broadly apply to the general population and are overwhelmingly driven by academic theory, lacking consideration of unique circumstances and lived experience (Coffey, 2022; Sollis et al., 2022).

Other approaches emphasise that wellbeing conceptualisations are inherently individual and context bound (Betley et al., 2023). To better reflect the experiences of wellbeing of different population groups, many studies have utilised participatory approaches to develop conceptualisations of wellbeing. A review of wellbeing frameworks developed using participatory methods by Sollis et al. (2022) demonstrated considerable variation in wellbeing conceptualisations across different population groups, highlighting the limitations of generalised wellbeing models. For example, connection to culture was demonstrated as a key element of wellbeing in 80% of the frameworks created with Indigenous populations, compared to only 6% of the frameworks created with predominantly non-Indigenous participants (Sollis et al., 2022).

Despite progress on population-specific conceptualisations of wellbeing, there is a lack of meaningful involvement of young people in wellbeing theory and measurement research. In Sollis et al.'s (2022) review, young adults were the least consulted of all age groups. The lack of youth involvement is concerning, given that their perspectives may deviate significantly from those of academics or health professionals. This includes young people living with chronic conditions, who are a growing proportion of the population that may have unique wellbeing needs (Wood et al., 2018). Currently, many of the wellbeing measures that are routinely used with young people with chronic conditions focus primarily on functional status or health related quality of life, and may not sufficiently capture what is important for this population's sense of wellbeing (Flannery & Jacob, 2020). In line with this, there is increasing recognition within government (Department of Health & Aged Care, 2019), clinical (Flannery & Jacob, 2020), and research (Hall et al., 2016) spaces of the importance of meaningfully involving young people with chronic conditions in the development of wellbeing models and measures that align with their perspectives.

Accordingly, the aim of this study was to develop an understanding of wellbeing that is rooted in the perspective of young people living with chronic health conditions. This will allow comparison between wellbeing as conceptualised by academic 'experts' to that of experts-by-experience, i.e., the target population. Our aim was to use Group Concept Mapping (GCM) to explore the perspectives of young people with chronic conditions. GCM is an integrated mixed method methodology that seeks input from a specific population on a concept under investigation (for a full overview, see Kane & Trochim, 2007). The multi-step process culminates in the development of a 'concept map', a visual representation of the numerous elements within the concept, demonstrating how individual elements group together to form different domains or themes relating to the concept. GCM was considered a suitable approach given the participatory nature of the technique, with the entire research process driven by the perspective of the participants.

2. Methods

2.1 Participant eligibility and recruitment

Ethics approval was received from the Human Ethics Research Committee of the University of Western Australia (approval number: 2021/ET000331). Participants were recruited from national chronic condition advocacy organisations representing conditions including chronic pain, arthritis, epilepsy, chronic fatigue, type 1 diabetes, and functional neurological disorder. Organisations were supplied with recruitment materials to be disseminated by mailing lists and social media. Individuals were eligible to participate if they (1) lived in Australia, (2) were aged between 16 and 25, (3) self-reported a diagnosis of one or more chronic physical conditions, and (4) had access to a computer to participate in the research. For the purposes of this study, a physical health condition was considered chronic if it persisted for longer than 6 months, required ongoing medical management, and impacted day to day functioning (Goodman et al., 2013). Given the small sample size required for GCM (Kane & Trochim, 2007), the researchers engaged in purposive sampling to ensure a variety of perspectives were represented in the participant pool. Interested parties were directed to contact the research team via email, with 17 potential participants doing so. 11 participants were selected by the research team, with an aim to maximise representation of various conditions, ages, and gender. For example, participants were first selected if they had a condition that was not reported by any other interested individual. When expressions of interest were received from multiple individuals with the same chronic condition, we selected 2-4 participants to represent these conditions by selecting those that could also contribute to age or gender diversity. As the majority of interested individuals were female, any individuals of other genders were also prioritised in selection. Participants were sent a Participant Information Sheet and Online Consent form to complete, with those under 18 years of age required to receive parental consent in addition to providing assent.

2.2 Group concept mapping methodology

Critical steps within the GCM process include preparing for the process, idea generation, statement structuring, analysis, and interpretation (For a full overview, see Kane & Trochim, 2007). Participants are engaged in the idea generation and statement structuring stages, while other stages are completed primarily by the research team and advisory group. Although each step is mandatory, there is flexibility in the methods used to achieve each step, with the specific procedures utilised in this project summarized below.

2.3 Lived experience engagement

The first and third author have lived experience of chronic conditions in childhood and youth. The first author collaborated with a pre-established advisory group of young people with chronic conditions in the project formulation and planning stage as well as during the interpretation stage. Members of the advisory group were reimbursed for their time at a rate of $35 per hour.

2.4 Preparation

Preparing for GCM involves determining your concept of interest and designing an appropriate focus prompt to elicit participants' ideas about this concept. The concept of wellbeing was chosen based on various discussions within the research team and with youth advisors on prior research projects, which suggested a discrepancy between youth perceptions of wellbeing and those provided by academic definitions. In an initial meeting, the advisory group collaborated with the first author to design the focus prompt for the study. This prompt is provided to participants to help them brainstorm ideas about the concept, and is commonly presented in a complete-the-sentence format (Kane & Trochim, 2007). The focus prompt developed for the current study was "I have a sense of wellbeing when…"

2.5 Statement generation and structuring

The purpose of this step was to develop a set of statements that could accurately capture the concept of 'wellbeing' in its entirety. In the current study, statement generation occurred in two online focus groups of four to five participants (nine participants in total, as two participants were unable to attend the scheduled groups) and facilitated by the first author. In focus groups, participants first generated as many statements about the topic of interest (i.e. wellbeing) as possible by completing the focus prompt, writing their responses on an anonymous online whiteboard accessed by all participants simultaneously (See figure 1). Afterwards, a group discussion took place, exploring trends in statements, reactions to different ideas, and the importance of various statements to overall wellbeing.

Figure 1. Example of online whiteboard after initial statement generation

I have a sense of wellbeing when...

Having a medical team who has my back

Authentic conversations

being able to be at school for the whole day

Just doing things without fear of being perceived as 'not sick enough'

I have the ability to prioritise my body

Going for a run if symptoms allow

Enjoying the ocean

being able to have fun with friends

Doing something I enjoy without having to think about it

Being able to speak for myself and voice my opinions

Having the time to read

When I get to do the little things, e.g. reading, listening to podcasts, fresh air, reality TV

Being able to relax

When I don't feel guilty for taking time to myself

Feeling understood/ heard

Glass of wine

I connect with others in pain or from the same chronic illness community

Organise my time well

When I am no longer fighting against my body

When I am able to dedicate time to my pain management

I feel oriented towards my goals and who I believe I authentically am

I am accepting of needing to engage in self-care

I attend a medical/health related appointment and feel heard

I feel safe

I can get out of bed with low fatigue levels

when I am playing with my pets.

I feel balanced

when I can do tasks at ease

I exhibit compassion towards others or myself

when I am doing something creative

I am snuggled up on the couch with a snack/ tea

when I have the support of my family/ friends

when I have accepted my symptoms/ illness

When I can go to the gym

When I can work effectively

When I can feel present with my partner/ friends/family

Am engaging all of my senses positively (e.g., on a walk outside)

My emotions are validated and supported by others

When I am actively choosing to learn something new

I can actually exercise

Being able to organise my social life

I do something I didn't think I would be able to

My friend/ partner/family member hugs me

when I believe in myself

I am talking with people who understand my experience

I don't let fatigue/ symptoms rule my day

Feeling financially stable

My pain levels are at their base level

I am living in the direction of my values

I can speak positively about myself

I'm doing something with my dogs

when my symptoms are manageable

A total of 144 statements on wellbeing were generated in the statement generation stage. As statements were generated by multiple focus groups, many of these ideas overlapped considerably. In addition, due to the positioning of the self in the focus prompt, several of the statements were very specific or contained multiple dimensions of wellbeing "e.g., I have a sense of wellbeing when I am spending time with my dog". A review of the statements was undertaken by the research team and advisory group which involved identifying and merging overlapping statements and rewriting highly specific statements to more broadly apply to the population. For example, the statements "I have of sense of wellbeing when I can go to the gym" and "I have a sense of wellbeing when I am able to go for a run" were merged into one statement; "I have a sense of wellbeing when I am able to exercise". This led to an amended list containing 62 statements about wellbeing.

In an online Qualtrics form, the final list of 62 statements was sent to participants who were asked to sort them into groups based on what made sense to them. Participants were required to sort every statement into a group and were instructed to create a minimum of two groups. Participants were reimbursed for their time completing the sorting activity with a $10 voucher to a retail outlet. Eleven participants completed the sorting activity, each creating between 2 and 16 groups, with a mean number of 6.8 groups.

2.6 Analysis

Analysis involved three steps and was completed using RStudio (version 2022.07.0) with the RCmap package, an R extension designed specifically for the GCM analysis (Bar & Mentch, 2017). The first step involved combining each participant's individual sorting data of the 62 statements into a group similarity matrix. For any pair of statements, the matrix contained a value denoting how many times these statements were sorted into the same group by all participants. Multidimensional scaling of the similarity matrix was used to place each of the statements as points on a two-dimensional plot, with statements more commonly sorted into the same group appearing closer together on the plot. A stress index computed from this analysis was used to judge the extent of the discrepancy between the original similarity matrix and the resulting map distances. The stress index was 0.29, which is similar to the average stress value across various GCM studies and provides evidence for the validity of the final map as a representation of the original statement groupings created by participants (Rosas & Kane, 2012).

Finally, hierarchical cluster analysis with the Ward2 algorithm was used to determine clusters of individual statements that may reflect higher-order domains of the 'wellbeing' concept. The resulting map was systematically inspected at each step of clustering from 15-3 clusters, leading the research team to conclude that a seven cluster solution was the most appropriate solution to authentically represent the participants' grouping and the concept as a whole. A bridging value was calculated for each statement; bridging values range between 0 and 1 and demonstrate the relationship of the statement to other statements on the map. A statement with a higher bridging value reflects a greater degree of variability in how each participant grouped this statement, suggesting that the statement may act as a 'bridge' or link between the cluster it is subsumed by to other clusters or statements. Statements with lower bridging values strongly reflect nearby statements and may be considered as conceptually 'anchored' to its' cluster, i.e. to purely reflect the core sentiments of the cluster it is subsumed by (Kane & Trochim, 2007). Mean bridging values for each cluster were calculated to judge cluster cohesiveness, with a higher mean value suggesting a cluster is composed of more disparate ideas than those with lower values. The resulting concept map was then presented to the youth advisory group, who collaborated with researchers to generate names for each of the seven clusters.

3. Results

3.1 Participants

Of the 11 participants, nine participants identified as female (81.8%), while one participant identified themselves as male (9.1%) and one as trans or gender diverse (9.1%). Participants ranged in age from 16 to 25 years, with a mean age of 21.9 years. Participants were located around Australia, with three (27.3%) from New South Wales and Western Australia, two (18.2%) from Victoria and Queensland, and one (9.1%) from Tasmania and South Australia.

Participants reported a diverse range of chronic conditions including chronic pain (n = 6, 54.5%), allergies (n = 4, 36.4) functional neurological disorder (n = 4, 36.4%), Ehlers Danlos syndrome (n = 3, 27.3%), endometriosis (n = 2, 18.2%) and inflammatory bowel disease (n = 2, 18.2%). The majority of participants (81.8%) reported being diagnosed with more than one chronic condition. 45.5% of participants had been diagnosed over five years ago, while 9.1%, 27.3% and 18.2% were diagnosed 3-4 years, 1-2 years, and less than a year ago, respectively.

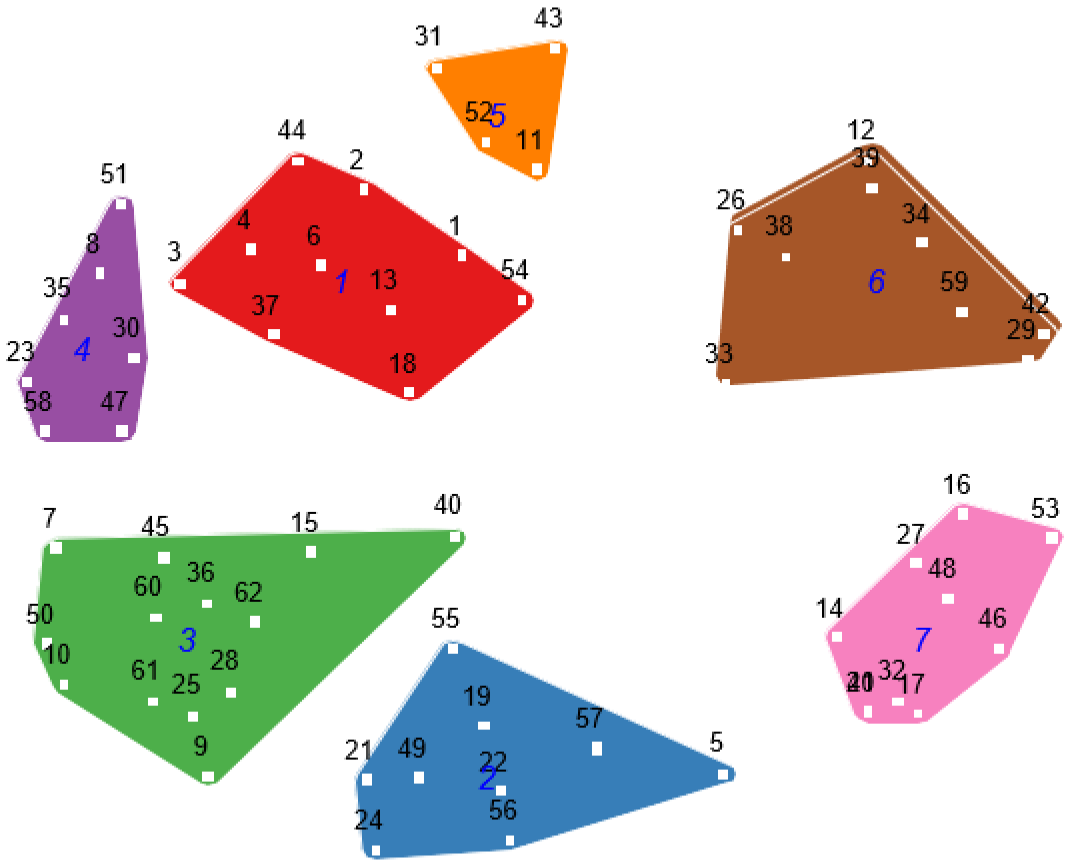
3.2 Resulting concept map

Following multi-dimensional scaling and hierarchical cluster analysis, seven clusters were displayed in the final concept map (Figure 2), (1) 'Embodying authentic self'; (2) 'Being a young person'; (3) 'Abilities and capacities'; (4) 'Self-understanding and nurturing'; (5) 'Hopeful future outlook'; (6) 'Supportive systems and communities'; and (7) 'Emotional support and validation'. Of the seven clusters, 'Hopeful future outlook' had the fewest statements (four) while 'Abilities and capacities' had the greatest number of statements (13). Maximum bridging values calculated for each statement ranged between 0.2 and 0.66, with higher values representing the likeliness of a statement acting as a 'bridge' that has links beyond its' determined cluster to other clusters on the map. Mean bridging values demonstrated that the most cohesive clusters were 'Abilities and capacities' (0.38) and 'Embodying authentic self (0.39), with the least cohesive cluster being 'Hopeful future outlook' (0.57). Table 1 provides a summary of each cluster with examples of statements that fell within it. A full list of statements, including bridge values for each statement, is available in the Appendix.

3.3 Cluster overview and interpretation

'Embodying authentic self' captures the importance for young people of knowing, understanding, and becoming an authentic and realised version of the self. In the naming session, young people emphasized the importance of this cluster's focus on the self, as opposed to the experience of having a chronic condition. The cluster 'Being a young person' had a similar emphasis on the self, with statements relating to different ways young people wish to engage with the world, such as attending school, engaging in hobbies, and "feeling like you have the capacity, the mental and physical capacity to connect with other people…" (P7, 22). This cluster was named after one youth advisor shared that the statement '*I have a sense of wellbeing when I can simply just be a young person,'* "honestly covers and captures all the other statements." In focus groups, participants described feeling like other people associated the activities in this cluster with youth or things that are 'normal' or 'should be easy' to do when you are young. However, these activities were often those that were disrupted by the experience of a chronic condition.

Figure 2. Final concept map of 'wellbeing', demonstrating 62 statements about wellbeing organised into 7 clusters



Note. The number of each cluster (1-7) is presented in the middle of the cluster and aligns with the cluster numbers in Table 1. The white squares and black numbers within each cluster represent the statement and respective statement ID number.

While 'Being a young person' was perceived to be about living freely and doing things you wanted, 'Abilities and capacities' was described as relating to activities of daily living (for example, preparing and eating meals, exercising, and engaging with others), including the things one must do to self-manage their condition. Participants described the 'burden' of having a chronic condition meant you were often unable to engage in desired activities and expressed the need to be able to have "a world outside my illness" (P6, 23) after attending to their health. The cluster name was chosen to reflect the idea that a sense of wellbeing involves the capacity to engage not only with the necessary activities for managing a chronic condition, but also the activities of broader life; to live instead of just survive. 'Abilities and capacities' was inherently condition focused and emphasised minimising the interference and burden of the chronic condition on the individual's life while promoting autonomy in their activities and ability to self-advocate. In doing so, this provided them with the opportunity to begin to engage in activities described in 'Being a young person'.

Table 1. Example statements for resulting wellbeing clusters

Cluster	Cluster description	Number of statements	Example statements completing the prompt 'I have a sense of wellbeing when…'
(1) Embodying authentic self	Knowing, understanding, and becoming an authentic and realised version of the self	10	I know exactly who I am I am living in the direction of my values I acknowledge and accept my feelings without criticism
(2) Being a young person	Engaging with the world through socialisation, education, hobbies, and other desired activities associated with being 'young'	9	I have desire and energy to interact with others I can simply just be a young person I am doing an activity I enjoy without having to think about it
(3) Abilities and capacities	Capacity to engage in self-care, condition management, and to minimise the impact of the condition on daily life.	13	I feel like I can manage my symptoms I have enough energy to do the things I want to do, not just the things I need to do I can do what I want to do without my symptoms interfering
(4) Self-understanding and nurturing	Treating oneself with compassion, understanding, and maintaining a positive perspective in light of challenging circumstances.	7	I practice self-care during difficult times I know when I need to pace myself throughout the day, and don't put excess pressure on myself I can focus on my strengths, even when my body is struggling
(5) Hopeful future outlook	Accepting the reality of one's chronic condition while maintaining positive expectations for the future	4	I have accepted my illness I feel hopeful about a 'healthy' future, or at least my version of healthy I can accept my diagnosis and enjoy my life, despite knowing that my condition may get worse in the future
(6) Supportive systems and communities	Environmental factors including secure housing, financial security, quality medical care and accessible public spaces	9	I have a safe place to life I feel heard by medical professionals Public places and communities take responsibility in meeting my accessibility needs, instead of putting the onus on me to ensure I can access them
(7) Emotional support and validation	Close relationships that provide acknowledgement, understanding, and allow authentic communication about life with a chronic condition	10	I feel emotionally supported by my family and friends I feel that I am seen and understood for who I am I am able to be authentic about feeling sick without fear of rejection or guilt

The clusters of 'Self-understanding and nurturing' and 'Positive future outlook' demonstrated how acceptance and adjustment may promote wellbeing when living with a chronic condition. 'Self-understanding and nurturing' captures the importance of having flexible self-expectations and treating oneself with compassion and care when dealing with a chronic condition that is uncontrollable and unpredictable. While this related to how young people responded to health challenges, the statements in this cluster were more self-focused, emphasising how young people treated themselves in light of these challenges, for example, by maintaining a positive and adaptable perspective and "not punishing yourself for needing to look after yourself" (P10, 16). 'Positive future outlook' relates to the ability of the young people to simultaneously accept their chronic condition and various prognoses while still maintaining a hopeful outlook for the future, with statements in this cluster reflecting the need to find a balance between these two often conflicting processes. Participants with stable conditions noted that acceptance meant understanding that their condition would be life-long, while participants with uncertain or potentially progressive diagnoses described the importance of reaching a place of acceptance to allow them to find mental peace and engage with life to the best of their ability.

Notably, the 'Positive future outlook' cluster was made up of just four statements (statements 11, 31, 43 and 52) and included the two statements with the highest bridging value (0.65) across all statements, statements 11 ('I have accepted my illness') and 43 ('I feel hopeful about my future health'). As higher bridging values indicate that these statements have links to other clusters on the map, this points towards greater variation in how each of the young people conceptualise the roles of acceptance and hope for the future. It is possible that for some participants, acceptance and hope were not conceptually similar experiences, and this led them to place the statements into separate clusters, leading to higher bridging values. Exploration of participant's individual sorting data supports this notion, with many participants sorting statement 43 into a different cluster than statements 11 and 52 ('I can accept my diagnosis and enjoy my life, despite knowing that my condition may get worse in the future'). This suggests that for some participants, accepting one's condition (statements 11 and 52) is seen as conceptually distinct from feeling hopeful for the future (statement 43), while for others, acceptance and hopefully are inherently linked.

The final two clusters broadly related to the role of others in wellbeing, with one cluster focusing on individual relationships and another representing greater society. Several participants felt that the role of others and society was inappropriately minimised in discussions about their wellbeing:

> Wellbeing is also in the hands of venues who need to be accessible and friends who need to be understanding and family who need to be supportive and medical professionals who need to also be supportive. Like it's, it's a whole group of people. It's not just us. (P5, 21)

The 'Emotional support and validation' cluster emphasises the importance of supportive relationships as well as the place of the chronic condition in interactions with loved ones. While many of the statements in the cluster reflected positive interactions with others more broadly, around half of statements focused specifically on interactions with others regarding their health. Young people expressed concerns that they would face misunderstandings or assumptions from others in various areas related to their condition. For example, when asking for emotional support due to health challenges, being provided with accessibility aids, or disclosing their condition to others. Given the considerable impact of their chronic conditions on their lives, the young people described the need for loved ones to create a safe space for them to be open and vulnerable without fear of judgement or abandonment. For example, one young person described the need for loved ones:

> To be able to go into every day, to see the bad days, to see the good days, to see the medication that you have to take and the appointments that you have to do, I think that's important. (P4, 25)

Wellbeing in this cluster was promoted by acknowledgement, empathy, and reassurance from those without lived experience of chronic conditions.

Statements in ‘Supportive systems and communities’ were highly varied and included having a safe place to live, financial stability, access to medical care, accessible community spaces and practical support from either family or professional carers. A key element of this cluster was good quality medical care, which for young people involved having a consistent team of health professionals who knew them, listened, and validated their experiences, “It’s important to have a team that, you know, you can trust” (P6, 23). Notably, many participants shared prior experiences where interactions with healthcare professional led them to feel unheard or disregarded. The importance of appropriate medical care was highlighted by one participant who shared reluctance to seek healthcare due to prior experiences:

> Mum and I have had really bad experiences presenting to emergency and like, recently... we noticed ourselves kind of avoiding presenting when maybe I needed to… like we know the people that would have to deal with me at our local hospital and we know we don't always have positive experiences with them, so then we just kind of try and do it ourselves, which isn't good. (P10, 16)

Participants also noted the complex interplay between typical youth experiences and having a chronic condition, “When you're a young adult moving out of home for the first time, it's a lot more difficult to find a place that's accessible and you can have your independence but have your support that you have, to still stay close to hospital.” (P1, 24).

The final map presents seven clusters each relating to a distinct aspect of wellbeing, such as interacting with others, active participation in valued activities, symptom management and young people’s relationship with themselves. Mean bridging values were lowest in clusters ‘Abilities and capacities’, ‘Embodying authentic self’, and ‘Emotional support and validation’, suggesting that wellbeing in these areas is experienced in a consistent way by most of the young people in the sample. In contrast, the mean bridging value for the ‘Positive future outlook’ cluster was considerably higher than the rest of the cluster means, suggesting additional nuance *within* the sample in how future perspectives relate to wellbeing.

4. Discussion

The aim of this study was to conceptualise wellbeing from the perspective of young people living with various chronic health conditions. The use of the group concept mapping methodology demonstrated seven clusters that contributed to a sense of wellbeing in young people. These are (1) ‘Embodying authentic self’; (2) ‘Being a young person’; (3) ‘Abilities and capacities’; (4) ‘Self-understanding and nurturing’; (5) ‘Hopeful future outlook’; (6) ‘Supportive systems and communities’; and (7) ‘Emotional support and validation’. These clusters were developed based on the participants’ generation and sorting of various wellbeing statements. As such, each cluster reflects what young people believe to be a distinct domain of their wellbeing, allowing comparison to existing academic and participatory-based conceptualisation of wellbeing (Sollis et al., 2022; Tov, 2018).

4.1 Comparisons to existing conceptualisations of wellbeing

It is apparent that while several clusters share similarities to those present in prior academic theories of wellbeing, statements within each cluster demonstrate specific nuances in how youth with chronic conditions perceive these domains. For example, the 'Emotional support and validation' cluster bears similarities to Ryff's (1989) wellbeing dimension of 'positive relationships with others', conceptualised as the presence of warm, trusting, relationships and the ability to empathise and deeply connect with others. However, for young people with chronic conditions, this domain reflects the additional necessity of these relationships to provide support and understanding specific to their health challenges.

Similarly, the 'Abilities and capacities' cluster in the current study in part related to young people's ability to manage the symptoms of their condition, demonstrating additional nuance in how physical health relates to wellbeing for youth with chronic conditions. Across wellbeing measurement instruments, physical wellbeing is a commonly assessed dimension (Linton et al., 2016), and more recent conceptualisations of human wellbeing and flourishing have included individual's physical health appraisals as a key component of wellbeing (Vanderweele, 2017). However, for youth with chronic conditions, it appears that the role of physical health in wellbeing is related to their perceived ability to manage the disease impact to the extent that it has minimal interference with desired activities. In this way, the statements in this cluster relate more to the concept of functional self-efficacy than to general appraisals of physical health (Ebrahimi Belil et al., 2018).

Considering how the seven domains highlighted in this study compare to those of other participatory wellbeing frameworks may distinguish elements of wellbeing that are specific to young people with chronic conditions from those that are broadly relevant to the general population. As demonstrated by Sollis et al. (2022), participatory based approaches to wellbeing conceptualisation have demonstrated unique facets of wellbeing across different populations. Over 30 wellbeing areas were identified from the 130 wellbeing models reviewed by Sollis et al. (2022), with family and other relationships, emotional wellbeing, and physical health domains represented in over 80% of the models. In contrast, less than 25% of the models included a wellbeing area related to identity and self-concept or aspirations for the future. This suggests that the clusters of 'Embodying authentic self' and 'Positive future outlook' in the current study may reflect nuances in wellbeing conceptualisations that are shaped by lived experience, such as living with a chronic condition as a young person. In line with this, making plans for the future and development of self-concept are key developmental tasks for young people (Wood et al., 2018), and this may be particularly important for young people with chronic conditions, whose experience of an illness may create future uncertainty or hinder their ability to act in alignment with their self-concept. In practice, adherence to generic wellbeing frameworks and instruments may lead to this area of wellbeing being overlooked in the care of youth with chronic conditions, providing an inaccurate understanding of the young person's wellbeing and the various contributing factors.

When considering established concepts of hedonic and eudaimonic wellbeing, the young people's ideas more commonly reflected eudaimonic components of wellbeing such as meaning-making, self-acceptance, authenticity, and value-based living. Hedonic components, such as feeling well and life satisfaction, were primarily described as secondary outcomes of eudaimonic wellbeing. This aligns with prior research demonstrating that youth with chronic conditions perceive overall life satisfaction as an outcome achieved through eudaimonic pathways such as self-determination, self-understanding and personal growth (McDougall et al., 2016). The relevance of eudaimonic wellbeing, which has been described as 'challenged thriving'(Ryff et al., 2021, p. p. 97), over hedonic wellbeing also makes sense in the context of the young people's experience. Young people living with chronic conditions are likely to experience more negative affect in response to the challenge of balancing health demands with developmental tasks (Wilson & Stock, 2019). As such, understanding wellbeing via eudaimonic concepts may be more accessible and relevant to young people with chronic conditions than hedonic concepts which emphasise subjective feelings.

4.2 The role of others in youth wellbeing

Several clusters reflected the relational and environmental components that are integral to youth wellbeing. The 'Emotional support and validation' cluster reflects the role of social support in facilitating wellbeing for young people living with chronic conditions. Satisfaction with the overall level of social support received is an equally strong predictor of emotional wellbeing for youth with and without a chronic health condition (Lynch Milder et al., 2023). However, the current study demonstrated that a key facet of this domain was support and validation related to the young person's experience of the condition, which has received less attention in prior literature. Kaushansky et al. (2017) undertook a qualitative study with youth aged 18-21, living with various chronic conditions. The results demonstrated that, while youth reported having strong social circles, they rarely disclosed their chronic conditions to peers for fear of being labelled or misunderstood. Young people in the current study expressed similar concerns, and it is likely that the need to balance seeking validation with minimising the risk of poor social response acts as a key barrier to wellbeing within this domain.

The 'Supportive systems and communities' cluster covered various elements of the social context including accessible public spaces, financial stability, and access to appropriate medical care. In line with this finding, longitudinal research has demonstrated that existing discrepancies in various wellbeing outcomes between adults with and without disability can be partially explained by their experience of barriers to participation in economic, community, leisure and social dimensions (Aitken et al., 2022). Similarly, Emerson et al. (2012) demonstrated that youth aged 15-29 who self-reported a disability demonstrated lower positive mental health, as well as higher depression and anxiety, than their peers. However, for each outcome, the majority of differences was accounted for by reduced access for youth with disabilities to social, community, and economic resources. Together, these findings provide further support for the foundational role of social context in the wellbeing of young people with chronic conditions.

4.3 Implications

The current findings demonstrate the importance of moving towards a broader relational view of wellbeing for young people with chronic conditions, supporting the notion that wellbeing is "a process, formed through interplay between structural, institutional and individual factors" (Coffey, 2022, p. 69). The young people's perspective on the inherent role of others in their wellbeing reflects prior calls in the literature for a greater focus on adapting policy and public systems to support individual wellbeing (Atkinson, 2013; Emerson et al., 2012).

The primary role of eudaimonic concepts in the young people's perspective on wellbeing has important implications for how wellbeing is conceptualised and measured in this population. Research demonstrates that measures currently being used to assess wellbeing in young people with chronic conditions are primarily hedonic, with eudaimonic components underrepresented in current assessment tools (Orth & Van Wyk, 2021). This is concerning for several reasons. Firstly to accurately assess wellbeing in young people, measurement tools must align with young people's perspectives on wellbeing (Flannery et al., 2017). Lack of inclusion of eudaimonic concepts may result in measures that are unable to capture young people's sense of purpose, self-development, and proactive engagement with life – all of which were implicated as key drivers of wellbeing in our concept map. Furthermore, there are concerns that words used in items assessing hedonic wellbeing may often inadvertently reflect physical health (Ryff et al., 2021). An example of this is the World Health Organisation's Wellbeing Index (WHO-5, 1998), which has been used to assess wellbeing of youth with chronic conditions in several studies (See Denny et al., 2014; Farrant et al., 2023; Thomsen et al., 2023). Of the five items on the WHO-5, items two ('I woke up feeling fresh and rested') and three ('I have felt active and vigorous') may be inappropriate for the measurement of wellbeing in individuals with chronic conditions, who are more likely to report sleeping difficulties or who may often feel fatigued despite adequate sleep. Thus, scores on hedonic measures may not be reflective of solely wellbeing in this specific population, confounding discrepancies between young adults with and without chronic conditions.

These findings may also inform how health care professionals conceptualise treatment for young patients. Notably, of the seven domains that contributed to wellbeing, only one ('Abilities and capacities') focused primarily on physical symptoms and functioning. The medical system has traditionally focused on management and reduction of the physical impact of health conditions (Carel, 2007). For the young people in this study, reduction of physical symptoms was seen as important because it allowed them to engage in activities that are typical for their developmental stage, which was a key component of being a 'normal' young person. This is in line with prior research demonstrating that young people with chronic conditions place a high priority on both meeting their own standards of 'normal' and being perceived as such by peers (Kaushansky et al., 2017; Wilson & Stock, 2019). As such, treatment regimens that reduce physical symptoms via restriction of participation in 'normal' youth activities are likely to have a contradictory effect, ultimately leading to impaired wellbeing for young people (Hart et al., 2016). Furthermore, given the nature of many chronic conditions, the potential for improving wellbeing by reducing physical symptoms is finite (Carel, 2007). The current findings demonstrate numerous pathways through which health professionals may support wellbeing for young people with chronic conditions including providing validation, promoting self-compassion, and encouraging self-development. Such efforts may be fruitful even in the case of physical symptoms that are uncontrollable or untreatable (Wilson & Stock, 2019).

4.4 Conclusions, limitations, and future directions

Limitations of the current study primarily relate to the lack of representativeness of the sample to the target population. Despite purposive sampling ensuring various ages and conditions were represented, individuals expressing interest in participating, and thus the final sample, were predominantly female. This may hinder the transferability of particular elements of the current concept map, for example, the 'Emotional support and validation' cluster may function differently or have less importance for youth of other genders given previously demonstrated differences in disclosure practices (Venema et al., 2023). Additionally, prior research in type 1 diabetes demonstrates differences in how each gender adapts to living with the condition, with females more likely to incorporate their condition into their identity (Kruger et al., 2023) and males more likely to distance themselves from it (O'Hara et al., 2013). Currently, it is unclear how such gender differences may shape the conceptualisation of wellbeing, and future research should aim to confirm these findings with a more diverse sample. In addition, a further limitation of the study is the lack of measurement of additional participant demographics such as socioeconomic status, employment, and ethnicity; given the demonstrated impact of these factors on wellbeing for individuals living with disability (Aitken et al., 2022; Emerson et al., 2012), this information would have been useful to contextualise the findings.

In interpreting the results of this study, additional consideration should be given to how participants' knowledge of the study aim may have primed their contributions during the idea generation phase. Participants were aware that the study was recruiting young people with chronic conditions, and that the aim of the study was to understand wellbeing from their perspective. It is possible that this knowledge led participants to focus more on aspects of their wellbeing that were proximal to their chronic condition experience. As such, the tendency for the participants' ideas to reflect eudaimonic over hedonic wellbeing concepts may be in part due to priming. Future studies could explore how eudaimonic, hedonic, and hybrid measures of wellbeing compare within this population. Alternatively, research could investigate the perspective of wellbeing from a broader youth sample, including those with and without chronic conditions, while collecting detailed demographics from participants. This would allow identification of youth with chronic conditions and their perceptions of wellbeing, without priming them to focus on wellbeing as related to their health.

Despite these limitations, this study has several strengths. Young people living with chronic conditions can be considered experts by virtue of their first-hand experience. Thus, without considering the unique perspectives of how young people themselves experience wellbeing, it is difficult to argue that we are accurately and comprehensively assessing their wellbeing (Carel, 2007). The high level of participant involvement in the current study is notable, given that the majority of existing participatory based approaches to defining wellbeing do not reach a meaningful level of participant involvement (Sollis et al., 2022). By involving young people throughout the entire research process, the current study reached a higher level of participation than 92% of the studies included in the review by Sollis and colleagues, strengthening the relevance of the current findings. In addition, by including youth with various chronic conditions, this study was able to demonstrate common factors contributing to wellbeing across different conditions, such as experiences with healthcare professionals, engagement in typical youth activities, and receiving support from loved ones. These common factors may be practical targets for trans-diagnostic strategies to improve wellbeing for young people with various chronic conditions.

The results of this study may inform selection or creation of wellbeing measures in future research and policy. Regarding selection, researchers should ensure measures used in this population emphasise eudaimonic concepts of wellbeing, and any measures with hedonic components should be examined carefully for overlap with physical health symptoms. In addition, measures that can capture the wellbeing components outlined in the current study should be prioritised. The research team plans to build on the current findings by confirming the cluster structure with a larger and more diverse sample, with an ongoing aim of adapting existing measures or developing new instruments to more appropriately assess wellbeing as experienced by youth with chronic conditions.

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Conflict of interest statement

The authors report no conflicts of interest.

Author contributions statement

Asha Parkinson: Conceptualisation, Methodology, Advisory group consultation, Focus group facilitation, Data structuring, Formal analysis, Writing – original draft, Writing – review and editing. Barbara Mullan: Methodology, Data structuring, Writing – review and editing, Supervision. Amy Finlay-Jones: Conceptualisation, Methodology, Data structuring, Writing – review and editing, Supervision.

Data availability statement

The data collected and analysed in the study are available from the corresponding author upon reasonable request.

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Appendix

Table A1. Full list of statements generated completing the prompt 'I have a sense of wellbeing when…'

Cluster	Statement	ID	Bridging Value
(1) Embodying authentic self	I feel oriented towards my goals and who I believe I authentically am	1	0.43
	I see purpose in life	2	0.34
	I can speak positively about myself	3	0.52
	I acknowledge and accept my feelings without criticism	4	0.30
	I believe in myself	6	0.27
	I am living in the direction of my values	13	0.43
	I believe I can achieve my goals in the future	18	0.34
	I show compassion towards others or myself	37	0.43
	I know exactly who I am	44	0.49
	I feel like I have control over my life	54	0.37
(2) Being a young person	I am praised for something I have actually worked hard for that is unrelated to my illness	5	0.41
	I am doing an activity I enjoy (e.g. hobbies, spending time with pets) without having to think about it	19	0.46
	I am doing something creative	21	0.59
	I have desire and energy to interact with others	22	0.46
	I am learning something new	24	0.48
	I can simply just be a young person	49	0.41
	I achieve something I didn't think I would be able to	55	0.30
	I am able to go to school/work	56	0.47
	I am having fun with family and friends	57	0.39
(3) Abilities and capacities	I have the time and energy to manage my condition	7	0.43
	I can do things independently and without assistance (e.g. making a meal, walking my dog)	9	0.59
	I can eat the foods I want to without complications	10	0.50
	I do something that engages my senses positively (e.g., listening to music, seeing/smelling something beautiful)	15	0.26
	I can do what I want to do without my symptoms interfering	25	0.46
	I can get out of bed in the morning and go about my day	28	0.42
	I have enough energy to do the things I want to do, not just the things I need to do	36	0.21
	I am able to speak for myself and voice my opinions	40	0.20
	I am able to exercise	45	0.43
	I feel like I can manage my symptoms	50	0.47
	I am able to think clearly, listen, and remember things easily	60	0.31
	I have energy	61	0.38
	I am able to have a life and not just survive	62	0.28

(4) Self-understanding and nurturing	I have the ability to prioritise my body	8	0.49
	I focus on what I can control, even when I can't control my condition	23	0.44
	I practice self-care during difficult times	30	0.44
	I can focus on my strengths, even when my body is struggling	35	0.38
	I know when I need to pace myself throughout the day, and don't put excess pressure on myself	47	0.28
	I give myself permission to rest	51	0.52
	I can label my symptoms and feelings	58	0.44
(5) Positive future outlook	I have accepted my illness	11	0.65
	I feel hopeful about a 'healthy' future, or at least my version of healthy	31	0.47
	I feel hopeful about my future health	43	0.65
	I can accept my diagnosis and enjoy my life, despite knowing that my condition may get worse in the future	52	0.50
(6) Supportive systems and communities	I can afford medical bills and still be financially stable	12	0.58
	I am able to afford things I want to do, after paying for medical costs	26	0.43
	I have practical support (e.g. someone helps me organise appointments)	29	0.56
	I can balance keeping my independence and getting support from others	33	0.39
	I can go about my day/life without having to constantly ensure I have health resources such as hospitals or bathrooms nearby	34	0.49
	I have a safe place to live	38	0.44
	I have access to good quality medical care where I live	39	0.55
	public places and communities take responsibility in meeting my accessibility needs, instead of putting the onus on me to ensure I can access them	42	0.52
	I feel heard by medical professionals	59	0.43
(7) Emotional support and validation	people accept my feelings about my own health condition and don't try to explain them	14	0.41
	my condition is validated by others, whether my symptoms are visible or invisible	16	0.56
	my emotions are validated and supported by others	17	0.37
	people check in to see how I am	20	0.36
	I can do things without fear of being perceived as 'not sick enough'	27	0.44
	I am talking with people who understand my experience	32	0.39
	I feel emotionally supported by my family and friends	41	0.36
	I feel that I am seen and understood for who I am	46	0.37
	I am able to be authentic about feeling sick without fear of rejection or guilt	48	0.37
	I don't feel guilty for my accessibility needs being 'catered' for	53	0.44

Note. Bridging values demonstrate the relationship between each statement and the other statements and clusters within the map. A statement with a higher bridging value may act as a ‘bridge’ or link between two different clusters, while statements with lower bridging values strongly reflect nearby statements and may be considered as ‘anchored’ to the cluster they are subsumed by.