ORIGINAL ARTICLE

Users' perspective on rehabilitation interventions for young adult cancer survivors: A group concept mapping study

Maria Aagesen[1] | Marc Sampedro Pilegaard[2,3] | May Aasebø Hauken[4] |
Eva Elisabet Ejlersen Wæhrens[2,5] | Karen la Cour[2]

[1]REHPA, The Danish Knowledge Centre for Rehabilitation and Palliative Care, Odense University Hospital, Department of Clinical Research, University of Southern Denmark, Odense, Denmark

[2]The Research Unit for User Perspectives and Community-based Interventions, the Research Group for Occupational Science, Department of Public Health, University of Southern Denmark, Odense, Denmark

[3]OPEN, Open Patient data Explorative Network, Odense University Hospital, Odense, Denmark

[4]Centre for Crisis Psychology, Faculty of Psychology, University of Bergen, Bergen, Norway

[5]The Parker Institute, Copenhagen University Hospitals Bispebjerg–Frederiksberg, Frederiksberg, Denmark

Correspondence
Maria Aagesen, REHPA, The Danish Knowledge Centre for Rehabilitation and Palliative Care, Odense University Hospital, Department of Clinical Research, University of Southern Denmark, Vestergade 13, DK-5800, 5700 Nyborg, Denmark.
Email: maagesen@health.sdu.dk

Abstract

Objective: We aim to identify and prioritise rehabilitation interventions to strengthen participation in everyday life for young adult cancer survivors (YACS) between 18 and 39 years, involving the perspectives of YACS and relevant stakeholders.

Methods: A group concept mapping study was conducted in Denmark from 2019 to 2020. Online, participants generated and sorted ideas followed by rating their importance. Multidimensional scaling followed by hierarchical cluster analyses were applied to generate a cluster rating map of the prioritised interventions, which participants validated at a face-to-face meeting. Finally, a concluding conceptual model of prioritised rehabilitation intervention for YACS was developed.

Results: The study involved 25 YACS, three family members and 31 professionals working with YACS. The conceptual model included 149 ideas classified into eight intervention components created by the participants: (1) Treatment and possibilities within the social and healthcare system, (2) Rights and Finance, (3) Education and Work, (4) Psychological problems, (5) Body and Everyday Life, (6) Peer-to-peer, (7) Sexuality and Relationships and (8) Family and Friends. All components were rated equally important, whereby 17 ideas across the eight components were rated very important.

Conclusion: This study indicates that rehabilitation of YACS should be composed of eight equally important intervention components requiring an interdisciplinary approach.

KEYWORDS
cancer survivors, everyday life, health services, neoplasms, rehabilitation, young adult

1 | INTRODUCTION

Worldwide, approximately 1 million young adults (18–39 years) are annually diagnosed with cancer. Due to improved cancer treatment, their 5-year survival rate exceeds 80% (Barr et al., 2016). Young adult cancer survivors (YACS), comprising individuals who have completed primary cancer treatment, differ from older counterparts as they are in a phase of life where they develop identity, establish relationships,

attend school or university, enter work life and establish their own families (Feuerstein, 2007; Janssen et al., 2021; Parsons et al., 2012; Warner et al., 2016; Zebrack, 2011). Hence, it is crucial to focus on YACS as a distinct group with needs different from those of other cancer survivors (Barnett et al., 2016; D'Agostino et al., 2011; Galán et al., 2018; Richter et al., 2015; Zebrack, 2009).

YACS often encounter a multiplicity of physical and psychological late effects caused by cancer and its treatment, for example, fatigue, lymphoedema, concentration and memory problems, sexual problems and psychological distress. This challenges their everyday life as per activities of daily living and social participation, including education, work and leisure (Janssen et al., 2021). Despite growing awareness that YACS differ from older counterparts, limited attention has focused on age-specific interventions addressing their specific needs (Telles, 2021). Given that YACS expectedly have a long life ahead of them, knowledge about how to address the complexity of their needs to strengthen their participation in everyday life is essential (Smith et al., 2016).

Strengthening participation in everyday life demands interventions embracing multifactorial needs and everyday life. Consequently, rehabilitation, a multicomponent intervention focusing on both the social, physical and psychological domains and the interaction between these, seems crucial (Wade, 2020). Prior research targeting YACS' needs primarily focused on single-component interventions, for example., solely focusing on promoting physical activity (Johnson et al., 2021; Rabin et al., 2011a; Valle et al., 2021, 2013) or reducing fatigue (Fauske et al., 2021). Moreover, age-specific rehabilitation for YACS has seldom been addressed (Hauken et al., 2014). Wherefore it is paramount to develop a multimodal intervention for this population. It is essential to ascertain viewpoints on the needs and preferences of those who will receive, use and deliver the rehabilitation interventions (O'Cathain et al., 2019; Skivington et al., 2021). This should increase the likelihood of feasible, sustainable and effective interventions (Kane & Rosas, 2018; O'Cathain et al., 2019). Therefore, this study aimed to identify and prioritise rehabilitation interventions to strengthen YACS' participation in everyday life by involving the perspectives of YACS and relevant stakeholders.

2 | METHODS

2.1 | Study design

The study was designed as an explorative study using group concept mapping (GCM), which is a specific and structured mixed-method participatory approach incorporating the perspectives of participants on a selected topic (Kane & Rosas, 2018; Trochim, 1989; Trochim & Kane, 2005; Trochim & McLinden, 2017). GCM is a powerful method for stakeholder engagement as participants are involved throughout the entire research process, from production to interpretation of data (Kane & Rosas, 2018). GCM has widely been used to plan

and develop interventions in healthcare (Nielsen et al., 2019; Strassheim et al., 2021; van Grieken et al., 2014; Wallace et al., 2018). In Nielsen et al. (2019)), GCM was applied to identify, organise and prioritise ideas on how to enhance activities of daily living ability for people with chronic condition. The findings were later used to develop the intervention 'A Better everyday LifE' (Nielsen et al., 2021).

The method involves a preparation phase followed by six phases: (1) brainstorming; (2) sorting and labelling; (3) rating; (4) generating a cluster rating map; (5) validating the cluster rating map; and (6) developing a final conceptual model (Trochim, 1989). The GCM process took place from August 2019 to March 2020.
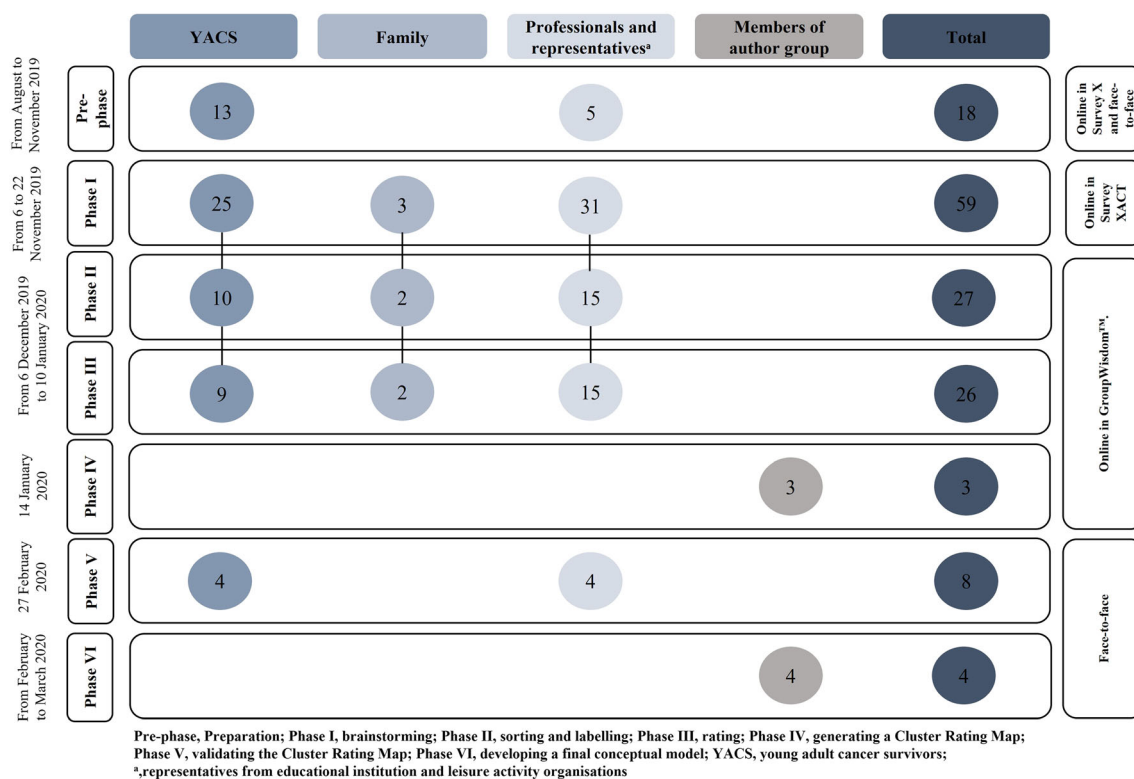
2.2 | Setting

The study was conducted online and face-to-face at REHPA, The Danish Knowledge Centre for Rehabilitation and Palliative Care (REHPA) (Figure 1).

2.3 | Participants and recruitment

Eligibility criteria for participants were (1) YACS between 18 and 39 years of age, (2) families and friends of YACS, (3) social and healthcare professionals in hospitals or municipality settings with clinical and/or research experience with YACS, (4) representatives from educational institutions and organisations working with YACS (patient organisation and leisure activity organisations, e.g., sports clubs) and (5) able to read and write Danish.

For the preparation phase, YACS were recruited through a residential rehabilitation stay at REHPA and professionals through networks for professionals working with YACS. For phases I–III, snowball sampling was used (Ghaljaie et al., 2017). Selected key stakeholders were contacted via e-mail with an information letter outlining the study's purpose, how and where the study would be conducted and the expected time required to participate. Relevant social media platforms posted the same information. Participants were encouraged to share the study information with other potential participants. To help assure a broad perspective on the topic, the recruitment was closely monitored to achieve a diverse group of participants in gender, age, partnership, geographical location, educational level, employment status, children, cancer diagnosis and months since diagnosis (the YACS), and on profession, type of workplace and experience of working with YACS (the professionals and representatives). When certain groups (e.g., men) were missing, persons representing these groups were encouraged to participate through posts on social media. If it was considered that the desirable diversity for a participant category was achieved, this group's recruitment and data was closed. For Phase V, the participants were purposively recruited via e-mail and focused on achieving diversity as described above.

Date	Phase	YACS	Family	Professionals and representatives[a]	Members of author group	Total	Method
From August to November 2019	Pre-phase	13		5		18	Online in Survey X and face-to-face
From 6 to 22 November 2019	Phase I	25	3	31		59	Online in Survey XACT
From 6 December 2019 to 10 January 2020	Phase II	10	2	15		27	Online in GroupWisdom™
	Phase III	9	2	15		26	
14 January 2020	Phase IV				3	3	
27 February 2020	Phase V	4		4		8	Face-to-face
From February to March 2020	Phase VI				4	4	

Pre-phase, Preparation; Phase I, brainstorming; Phase II, sorting and labelling; Phase III, rating; Phase IV, generating a Cluster Rating Map; Phase V, validating the Cluster Rating Map; Phase VI, developing a final conceptual model; YACS, young adult cancer survivors; [a],representatives from educational institution and leisure activity organisations

FIGURE 1 Flow chart illustrating the number of participants in the different phases and participation methods

2.4 | Data collection

2.4.1 | Preparation phase

A focus prompt was formulated to stimulate participants' reflections about the chosen topic: *What interventions do YACS need to participate in everyday life?* This was piloted among YACS in a face-to-face meeting at REHPA to ensure that the question was understandable. The YACS requested everyday life to be elaborated with examples to clarify the concept and the word 'interventions' to be replaced by 'services' as this made better sense to them. Therefore, we used 'services' in the final prompt and the dialogue with the YACS. However, in the manuscript, we use the word 'intervention'.

2.4.2 | Phase I: Brainstorming

In this phase, typically, 10 to 40 participants are required to achieve saturation in the brainstorming, and a set of 80 to 100 statements are generally reasonably to process in subsequent steps (LaNoue et al., 2016; Trochim & McLinden, 2017). To access Phase I, participants used a link to an online survey in SurveyXact received by e-mail or on a social media platform. First, the participants gave informed consent and answered questions on demographic data (age, sex, cancer diagnosis and months since diagnosis, profession and workplace). Then they were asked to suggest ideas based on the following focus prompt:

'What services do YACS need to participate in everyday life, comprising work, education, leisure, and social activities?'

When Phase I was completed, the main author split ideas containing more than one idea into separate ideas and removed duplicates (Kane & Rosas, 2018). For example, 'services addressing mindfulness and massage' was split into 'service addressing mindfulness' and 'service addressing massage'. Hereafter, it was checked by a second author, and any uncertainties were solved through consensus-based discussion between the authors. The final ideas were used in phases II–III.

All data in this phase was managed using the Research Electronic Data Capture (REDCap) electronic data capture tool hosted at the Region of Southern Denmark (Harris et al., 2009; Harris et al., 2019).

2.4.3 | Phases II and III: Sorting, labelling and rating

Participants from Phase I was invited to phases II–III by receiving an e-mail including a link to an online programme, designed for the GCM process: Concept System® GroupWisdom™ software: Concept Systems, Inc. Copyright 2004–2020; all rights reserved (hereafter: GroupWisdom™) (The Concept System® groupwisdom™, 2021). In this programme, the participants sorted the ideas from Phase I into meaningful piles and labelled each pile with a describing name for the content. They were not allowed to sort all ideas into one pile, but no

other restrictions were outlined. Following this, each participant rated the importance of each idea on a 5-point Likert scale (1 = *not important* to 5 = *very important*). Reminder e-mails, including a link to the online programme, were sent three times within 1–2 weeks.

2.4.4 | Phase IV: Generating a cluster rating map

Based on data from phases I–III, the GroupWisdom™ software was used to generate a cluster rating map, representing a visual presentation of how the participants grouped the ideas thematically into clusters with an average rating of importance for each cluster. More layers of clusters indicate a higher mean importance rating (The Concept System® groupwisdom™, (2021). Ithaca, NY'.; Kane & Rosas, 2018; Trochim & Kane, 2005; Trochim & McLinden, 2017).

2.4.5 | Phase V: Validation of the cluster rating map

To validate the cluster map, the participants took part in a face-to-face meeting at REHPA. At the meeting, we handed out the following set of recommended materials to the participants: the ideas, cluster list, point map, cluster map, point rating map and cluster rating map (Trochim, 1989). The authors facilitated a group discussion where the participants reached a consensus on the placement of ideas and cluster names. Hence, the participants could change cluster names and move ideas to other clusters if they thought the ideas better matched the cluster's topic.

2.4.6 | Phase VI: Developing a final conceptual model

Based on the input from the validation meeting in Phase V, the authors constructed a final conceptual model illustrating relevant intervention components for YACS.

2.5 | Data analysis

Demographic data were presented using numbers and percentages. The analyses were performed in Statistical Package for Social Sciences software 26.0 (IBM Corp, 2019).

In phases II and III, data from each participant were included in the multidimensional scaling analysis if at least 75% of the ideas were sorted, piles were labelled and there were no more than five missing ratings (Nielsen et al., 2019). The rating of importance is presented as median (range). Two analyses of the rating data were conducted: (1) calculation of a median for the importance of each idea across the participants and (2) calculation of a median of the medians of the importance of ideas within each cluster. Ideas rated as very important (median = 5) were presented separately.

In Phase IV, data analyses were performed in GroupWisdom™ ('The Concept System® groupwisdom™ (Build 2021.24.01) [Web-based Platform]. (2021). Ithaca, NY'). A similarity matrix, which shows the frequency of how many times ideas were sorted together, was generated based on the sorted data (Kane & Rosas, 2018; Trochim & McLinden, 2017). Then, a multidimensional scaling algorithm was applied to the data, and this analysis resulted in a point map illustrating how the ideas are sorted together. Ideas often sorted together appear closer on the map than items not frequently sorted together. The multidimensional scaling analysis produces a stress value, a goodness-of-fit, indicating how well the data from the similarity matrix fits with the multidimensional scaling solution (Rosas & Kane, 2012). Lower stress values indicate a better fit and in GCM studies, a stress value between 0.20 and 0.36 suggests that data are interpretable (Rosas & Kane, 2012).

Following the multidimensional scaling analysis, a cluster map was generated using hierarchical cluster analysis. The size and shape of the clusters are constructed by connecting the outer ideas in each cluster, and the size indicates how broad the meaning of cluster's content (Kane & Rosas, 2018; Trochim & McLinden, 2017). First, we commanded the GroupWisdom™ software programme to generate a four-cluster map. When examining the content of these clusters, it was evident that they represented rather diverse ideas. Therefore, we progressed to a five-cluster map and examined the two new clusters to determine if splitting them made sense, that is, if they represented different topics. Since they did, we continued to generate a six-cluster map, looked at the next split of a cluster into two, determined if the split made sense and so forth. We continued this process until split clusters seemed to represent the same topic. Based on the labels provided by the participants in Phase II, cluster labels were suggested by GroupWisdom™ (Kane & Rosas, 2018; Trochim & McLinden, 2017). Hereafter, a cluster rating map, that is, the cluster map with average cluster ratings overlaid, was generated based on the chosen cluster map (Kane & Rosas, 2018; Trochim & McLinden, 2017). Lastly, based on the extraction of data from the ideas, we summarised a description of each cluster.

2.6 | Ethics

The study was conducted following national and international standards of good research and followed the Declaration of Helsinki (World Medical Association, 2013). Approval from the Danish Data Protection Agency was given (number: 19/36061). According to the Danish law (cf. Committee Act, section 14, subsection 2), questionnaire and interview surveys do not require approval by Ethical Committees within Health Research. Hence, the Danish Regional Committee on Health Research Ethics decided that ethical approval was unnecessary (number: 20192000-113). All participants received written information about the study and gave informed consent. Sensitive personal data were stored in REDCap or at a secure SharePoint site hosted in the Region of Southern Denmark.

TABLE 1 Demographic data of young adult cancer survivors (YACS)

	Phase I: brainstorming (n = 25)	Phases II–III: sorting, labelling and rating (n = 11)	Phase V: validating the cluster rating map (n = 4)
	n (%)	n (%)	n (%)
Age			
18–29 years	6 (24)	0 (0)	0 (0)
30–39 years	19 (76)	11 (100)	4 (100)
Sex			
Female	20 (80)	8 (72)	4 (100)
Male	5 (20)	3 (28)	0 (0)
Partnership (yes)	17 (68)	9 (82)	3 (75)
Children (yes)	7 (28)	4 (36)	0 (0)
Geographical location			
The Capital Region of Denmark and the Region Zealand	10 (40)	6 (55)	1 (25)
The Region of Southern Denmark	6 (24)	2 (18)	2 (50)
The North Denmark Region and the Central Denmark Region	9 (36)	3 (27)	1 (25)
Highest educational degree[a]			
University/university college	18 (72)	10 (91)	4 (100)
Senior high school	7 (28)	1 (9)	0 (0)
Employment status at diagnosis			
Working	15 (60)	6 (55)	2 (50)
Studying	7 (28)	4 (36)	2 (50)
Others[b]	3 (12)	1 (9)	0 (0)
Type of cancer			
Gynaecological cancer	4 (16)	0 (0)	0 (0)
Breast cancer	5 (20)	3 (28)	2 (50)
Hodgkin's or non-Hodgkin's lymphoma	6 (24)	2 (18)	0 (0)
Testicular cancer	3 (12)	2 (18)	0 (0)
Others[c]	7 (28)	4 (36)	2 (50)
Months since diagnose			
0–12 months	9 (36)	1 (9)	1 (25)
13–24 month s	4 (16)	3 (27)	1 (25)
Over 24 months	12 (48)	7 (64)	2 (50)
Treatment received[d]			
Surgery	20 (80)	10 (91)	3 (75)
Radiation	11(44)	7 (64)	0 (0)
Chemotherapy	15 (60)	6 (55)	2 (50)
Other[e]	5 (20)	4 (36)	3 (75)

Abbreviations: SD, standard deviation; YACS, young adult cancer survivors.

[a]The classification is based on International Standard Classification of Education (ISCED 97).

[b]For example, maternity leave and unemployed.

[c]For example, lung cancer, brain tumour, malignant melanoma and renal cancer.

[d]Multiple answers were possible.

[e]For example, immunotherapy and anti-hormone therapy.

3 | RESULTS

The demographic characteristics of the participants are summarised in Tables 1 and 2. YACS and professionals were represented in all phases. Family and representatives from educational institutions and organisations working with YACS were represented in phases I–III. The exact distribution of participants across the different phases is presented in Figure 1.

TABLE 2 Demographic data of family, professionals and representatives from educational institution and leisure activity organisations

|	Phase 1: Brainstorming		Phases II–III: Sorting, labelling and rating		Phase V: Validating the cluster rating map	
	Family (n = 3)	Professionals and representatives[a](n = 31)	Family (n = 2)	Professionals and representatives[a](n = 16)	Family (n = 0)	Professionals and representatives[a](n = 4)
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Sex						
Female	3 (100)	28 (90)	2 (100)	14 (88)	-	3 (75)
Male	0 (0)	3 (10)	0 (0)	2 (12)	-	1 (25)
Geographical location						
The Capital Region of Denmark and the Region Zealand	1 (33)	16 (52)	0 (0)	10 (63)	0 (0)	4 (100)
The Region of Southern Denmark	0 (0)	9 (29)	0 (0)	5 (31)	0 (0)	0 (0)
The North Denmark Region and the Central Denmark Region	2 (67)	6 (19)	2 (100)	1 (6)	0 (0)	0 (0)
Relation to YACS						
Partner	2 (67)	-	2 (100)	-	-	-
Sibling	1 (33)	-	-	-	-	-
Profession						
Registered nurse	-	13(42)	-	8 (50)	-	1 (25)
Physiotherapist	-	4 (31)	-	1 (6)	-	1 (50)
Occupational therapist		2 (6)		1 (6)		1 (50)
Social worker	-	3 (10)	-	2 (12)	-	1 (25)
Other[b]	-	9 (29)	-	4 (26)	-	0 (0)
Years working with YACS						
Under 5 years	-	14 (45)	-	8 (50)	-	1 (25)
6–10 years	-	7 (23)	-	2 (12)	-	2 (50)
Over 10 years	-	10 (32)	-	6 (38)	-	1 (25)
Workplace						
Hospital	-	16 (51)	-	10 (63)	-	1 (25)
Municipality	-	7 (23)	-	3 (18.5)	-	3 (75)
Other[c]	-	8 (26)	-	3 (18.5)	-	0 (0)
Type of work						
Clinical	-	15 (48)	-	6 (38)	-	4 (100)
Clinical and research	-	11(36)	-	7 (43.5)	-	0 (0)
Other[d]	-	5 (16)	-	3 (18.5)	-	0 (0)

Note: "-" means not applicable.

Abbreviation: YACS, young adult cancer survivors.

[a]Representatives from educational institutions and organisations working with YACS, for example, patient organisation and leisure activity organisations, for example, sports.

[b]For example, doctor, dietitian and student counsellor.

[c]For example, university and sports club.

[d]For example, administration, quality development, study counselling and research.
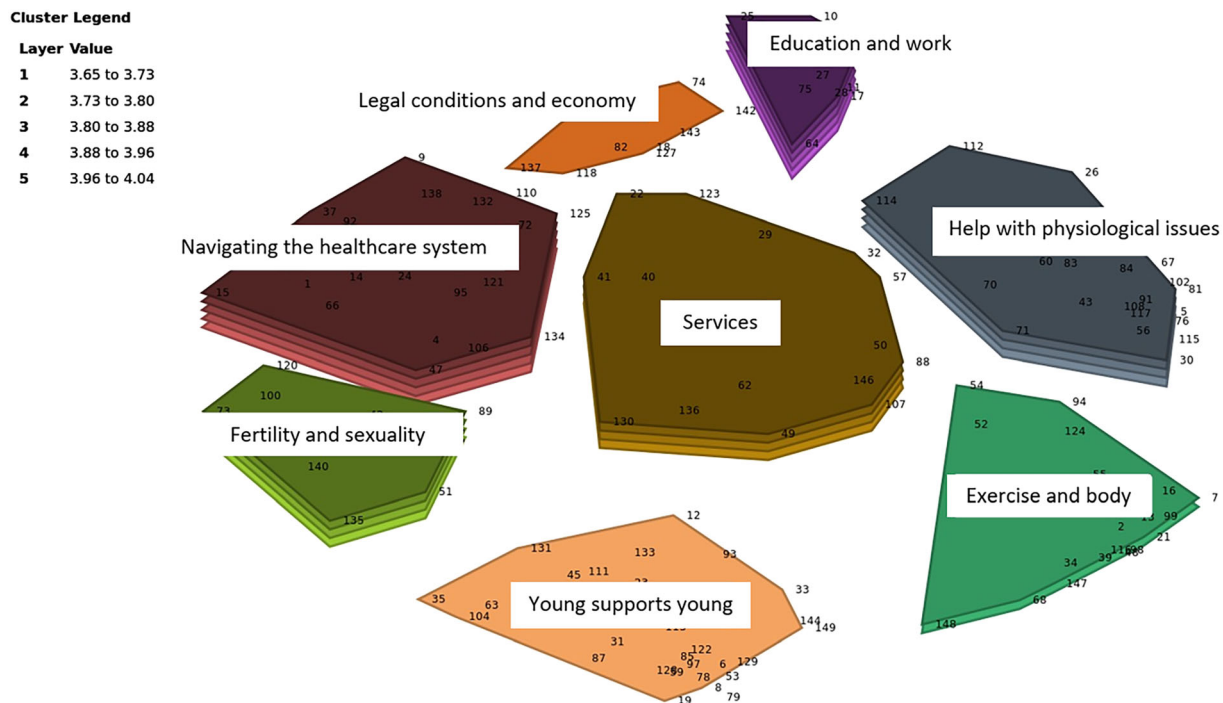
FIGURE 2 The cluster rating map before the validation meeting in Phase V. The numbers correspond to the ideas within each cluster (Appendix A). The size and shape of the clusters are constructed by connecting the outer ideas in each cluster, and the size indicates how broad the meaning of the cluster's content is. More layers indicate a higher mean importance rating of that cluster (e.g., clusters with one layer have a mean importance rating between 3.65 and 3.73, and clusters with five layers have a mean importance rating between 3.96 and 4.04) (Kane & Rosas, 2018; Trochim & Kane, 2005; Trochim & McLinden, 2017).

3.1 | Identification and organisation of ideas

In Phase I, the 59 included participants generated 339 ideas that were condensed to 149. In Phase II, the 149 ideas were sorted into four to 33 piles (median = 12). All sorting and labelling met the criteria for inclusion. Multidimensional scaling resulted in a point map with a stress value of 0.31, indicating an acceptable map. Cluster solutions from six to 10 clusters were applied, and the authors reached a consensus on a solution with eight clusters (Figure 2).

3.2 | Prioritising the ideas

All rating data generated in Phase III met the criteria for inclusion in the analysis. Due to the small number of family participants, their data were presented with data for YACS. This was the same for representatives from educational institutions and organisations working with YACS. Hence, their data was presented together with the professionals. Across participants rated most of the ideas as important (median = 4). Seventeen (11%) ideas were rated as very important (median = 5) (Table 3), and 'Education and Work' contained the highest number of high-rated ideas (n = 4). The medians of medians of the ideas within the clusters were equal (median = 4) (Table 4). In Appendix A, the median across the participants for each idea and the median of medians of the ideas within each cluster are presented for the entire group, YACS and family and professionals/representatives.

3.3 | Validation of the cluster map

At the validation meeting (Phase V), the eight participants moved 36 (25%) of the ideas to other clusters. The cluster named 'Services' was deleted, a new cluster, 'Family and Friends' emerged and six out of seven cluster labels were changed, resulting in the following eight clusters: (1) Treatment and possibilities within the social and health-care system, (2) Peer-to-peer, (3) Rights and Finance, (4) Education and Work, (5) Body and Everyday Life, (6) Psychological problems, (7) Sexuality and Relationships and (8) Family and Friends. Each cluster contained six to 30 ideas. The ideas were concrete (e.g., counselling about family life, roles and expectations for each other) and overall (e.g., help with returning to work). A complete list of the numbered ideas sorted into eight clusters is presented in Appendix A. In Table 4, a description of each cluster is presented.

Figure 3 presents the final conceptual model illustrating the eight clusters, each representing an intervention component. The content in 'Treatment and possibilities within the social and health primarily relates to structural and organisational conditions, which are preconditions for delivering and participating in rehabilitation. Hence, this intervention component encircles the YACS in the model's center'. 'Peer-to-peer' is presented as an oval as it is recurring in all intervention components. The model illustrates a preference for age-appropriate rehabilitation due to the desire for peer-to-peer support and ideas relating to age-specific challenges. The text under the larger circle illustrates the call for multiple professional competencies as the

TABLE 3 Overview of cluster names and ideas rated as very important

Cluster names and ideas rated as very important (n = 17)	Median (range)		
	Total (n = 26)	YAC/family (n = 11)	Professionals/representatives (n = 15)
Education and work (n = 4)			
17 Help to return to work	5 (2–5)	5 (4–5)	4 (2–5)
20 Support for return to work; how to handle it—Help with structure regarding number of hours	4 (2–5)	4 (3–5)	5 (2–5)
75 Cooperation between the cancer rehabilitation unit, the job centre and the employer	5 (3–5)	4 (3–5)	5 (3–5)
105 Social worker advice in relation to returning to or remaining in education	4 (2–5)	4 (2–5)	5 (2–5)
Treatment and possibilities within the social and healthcare system (n = 3)			
1 Better information about existing opportunities/services (e.g., groups, social worker and young cancer)	4 (3–5)	5 (4–5)	4 (3–5)
80 Easy access to professionals who may be needed: Sexologist, psychologist, dietitian, physiotherapist, social worker and so forth	5 (3–5)	4 (3–5)	5 (3–5)
130 Attention and treatment of late effects	5 (3–5)	5 (3–5)	5 (4–5)
Psychological problems (n = 3)			
5 Individual conversational therapy for the anxiety/fear of death implied by the cancer diagnosis	5 (3–5)	5 (3–5)	4 (3–5)
43 Conversations with a psychologist	4 (2–5)	5 (3–5)	4 (2–5)
81 Offer of help with psychological issues	5 (2–5)	5 (4–5)	4 (2–5)
Family and friends (n = 3)			
24 Guidance and direction on how to talk with own children about terminal illness in an appropriate way	5 (3–5)	5 (4–5)	4 (3–5)
54 Conversation/psychological help for the whole family about what they have come through and the new chapter that awaits	5 (3–5)	5 (2–5)	4 (3–5)
126 Help to speak with children who are relatives	5 (2–5)	5 (4–5)	4 (2–5)
Body and everyday life (n = 2)			
99 Help with rehabilitation	5 (3–5)	5 (4–5)	5 (3–5)
116 Physical activity	4 (3–5)	4 (3–5)	5 (4–5)
Peer-to-peer (n = 2)			
23 Groups to talk with other young/younger adults with a cancer diagnosis	4 (2–5)	4 (3–5)	5 (2–5)
59 Opportunity to meet other young adults with cancer	4 (3–5)	4 (3–5)	5 (3–5)

Note: Medians equal to five is highlighted with bold as five correspond to very important.

intervention components span a broad range. Lastly, the text above the larger circle illustrates that counselling, guidance, information, knowledge, support, coaching and access are prominent across all the intervention components.

4 | DISCUSSION

This study aimed to identify and prioritise rehabilitation interventions to strengthen YACS' participation in everyday life, involving the perspectives of YACS and relevant stakeholders. Informed by a range of relevant stakeholders, we successfully identified the following eight intervention components that were rated equally important: (1) Treatment and possibilities within the social and healthcare system, (2) Peer-to-peer, (3) Rights and Finance, (4) Education and Work, (5) Body and Everyday Life, (6) Psychological problems, (7) Sexuality and Relationships and (8) Family and Friends. Seventeen ideas across the intervention components were rated as very important.

The identified intervention components are largely in line with existing research (Baird et al., 2019; Rabin et al., 2011b, 2013; Tsangaris et al., 2014; Zebrack, 2009; Zebrack et al., 2006, 2007). However, this study contributed to the existing knowledge by generating numerous specific and actionable strategies to address YACS

TABLE 4 An overview of the content of each cluster, suggested delivery methods across the clusters and the rating of importance for each cluster

Cluster names (number of ideas in cluster)	Summary of content	Rating of importance[a] median (range)
Treatment and possibilities within the social and healthcare system (n = 29)	Guidance, knowledge or information about: • Cancer and late effects • Possibilities for rehabilitation in the social and healthcare system Access to: • Support by professionals through the cancer trajectory and the social and healthcare system • Needs assessment • Social and healthcare professionals with knowledge within young adults with cancer	4 (3–5)
Rights and Finance (n = 10)	Counselling, guidance or knowledge concerning: • Rights within the social and healthcare system • Financial issues, for example, insurance and subsidies • Legal advice • Notification of illness • Practical support at home	4 (3–4)
Education and work (n = 18)	Support or information regarding: • Maintaining and returning to work • Maintaining and returning to education	4 (4)
Psychological problems (n = 17)	Knowledge, coaching or support regarding: • Fear of recurrence and death • Emotional challenges • Anxiety • Thoughts for the future • Existential questions such as the death and identity	4 (4–5)
Body and everyday life (n = 30)	Guidance or knowledge regarding: • Physical and mental training • Physical activity • Diet • Strategies to manage social life and structure everyday life • Energy conservation • Cognitive challenges Access to: • Physical and mental training	4 (2–5)
Peer-to-peer (n = 29)	Access to: • Activities and forums where young adults with cancer can meet other young adults With cancer	4 (3–4)
Sexuality and relationships (n = 6)	Counselling or guidance regarding: • Relationship • Family life • Fertility • Sexuality	4 (4)
Family and friends (n = 10)	Counselling, guidance, support or information regarding: • Involvement of family and friends • Conversation with own children about terminal illness • Conversation with family and friends about cancer and the future • Cancer and late effects	4 (3–5)

[a]Calculated as the median of the medians of the ideas within each cluster.

rehabilitation needs, which have been lacking in previous research (Baird et al., 2019; Rabin et al., 2011b, 2013; Tsangaris et al., 2014; Zebrack, 2009; Zebrack et al., 2006; Zebrack et al., 2007). For example, ideas such as help with structure regarding the number of hours when returning to work help with energy conservation including prioritising activities in everyday life, counselling together with partners on the anxiety/fear of death implied by the cancer diagnosis, psychological counselling for the whole family about what they have been
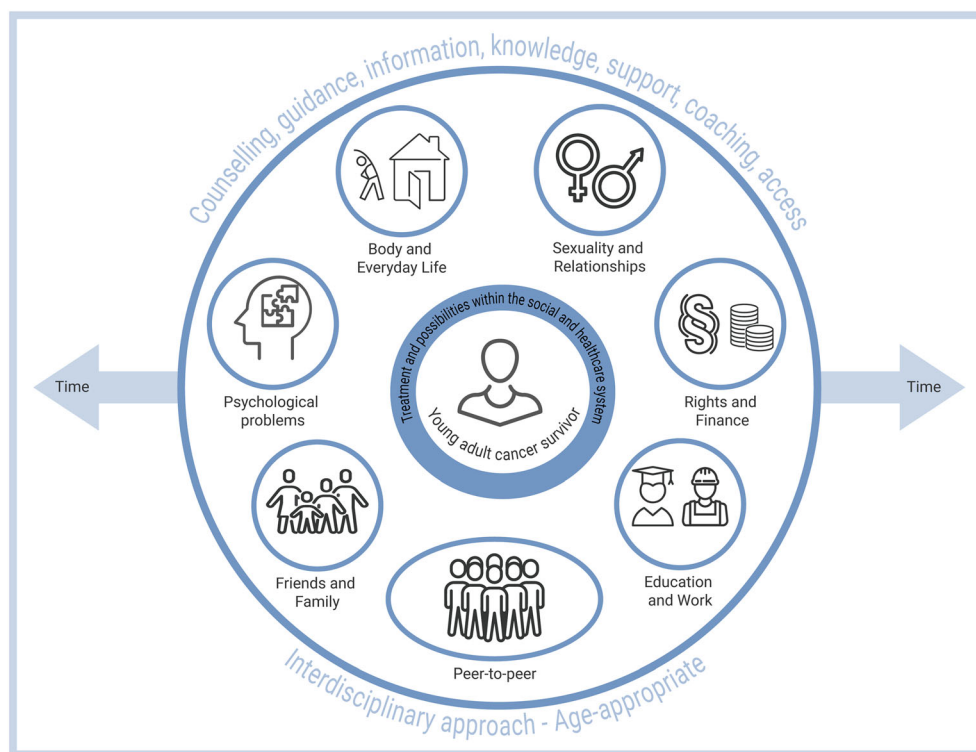
FIGURE 3 Model of identified rehabilitation intervention components for young adult cancer survivors to strengthen their participation in everyday life. Legend: The cluster *treatment and possibilities within the social and healthcare system* encircles the young adult cancer survivor in the model's centre as the content primarily relates to structural and organisational conditions, which are a precondition for delivering and participating in rehabilitation. *Peer-to-peer* is presented as an oval as it is a distinct intervention component but also overlaps with other components containing elements of peer-to-peer support. The *time arrow* illustrates that the importance and relevance of the intervention components depend on the individual's cancer trajectory and life situation at a particular time point and that the period for the intervention components is not predefined.

through and the new chapter that awaits and themed evenings about fertility, late effects, medical cannabis and existential issues (Appendix A for more suggestions).

Peer-to-peer support was identified as one of the intervention components and a recurring element across all the components. The importance of peer-to-peer support is not surprising, as sharing experiences with peers who share similar circumstances is found to help the individual coping with stressful events (Kowitt et al., 2019). Existing research among YACS shows that connecting with other survivors is highly valued and an essential aspect of the healing process (Kent et al., 2012; B. Zebrack et al., 2006; Zebrack et al., 2007). Furthermore, research shows that peer-to-peer support prevents social isolation and promotes psychological and physical functioning and overall quality of life in YACS (Treadgold & Kuperberg, 2010; Trevino et al., 2013). Despite the positive benefits of peer-to-peer support, other researchers have found that YACS is a lesser extent, offered this kind of intervention as part of rehabilitation (Benedict et al., 2021). Our findings suggest that physically based exercise groups tailored for YACS, municipality rehabilitation with peers and communities of other young adults in the hospital setting could be ways of targeting peer-to-peer support.

The participants rated all intervention components equally important, suggesting that future rehabilitation for YACS must be multicomponent and interdisciplinary. It may be challenging to address all intervention components simultaneously and for the individual; some intervention components will probably be more important than others depending on where in the cancer trajectory and life the individual is. This must be considered when developing future rehabilitation programmes by developing flexible and individual-tailored rehabilitation.

'Education and Work' contained the highest number of high-rated ideas ($n = 4$), which all refers to support and help with return to work/education. This confirms previous research, which has found that support for YACS and key stakeholders regarding work/education will enhance return to work/education (Elsbernd et al., 2018; Kosola et al., 2018; Pedersen et al., 2018; Stone et al., 2017; Vetsch et al., 2018). An American study showed that unemployed YACS receiving vocational rehabilitation were four times more likely to be employed than those not receiving such support (Strauser et al., 2010). Our results and earlier findings indicate that more information for faculties on how late effects can challenge participation in education would be beneficial to enhance return to education (Elsbernd et al., 2018).

This study provides participatory data that can be used on individual and group levels by both YACS, clinicians, social- and healthcare managers and researchers. YACS can use the conceptual model and the ideas to become aware of their needs in increasing their participation in everyday life. Clinicians can use the conceptual model with YACS to ensure that all potential rehabilitation needs to strengthen YACS participation in everyday life are assessed and addressed. Each profession involved in rehabilitation for YACS can also use the ideas to qualify the content of their intervention and ensure that the intervention is based on the users' preferences. The social- and healthcare managers can use this study to argue the importance of rehabilitation services for YACS. In addition, they can use the result to inform the development or improvement of existing content of local rehabilitation services for YACS. The ideas rated as very important (Table 3) can help the managers to prioritise where to start or what to focus on. Lastly, researchers can use generated data and the conceptual model in the design process of developing rehabilitation for YACS.

4.1 | Methodological considerations, strengths and limitations

A strength of employing the GCM method is that the data are predominantly generated, analysed and interpreted by the participants minimising the risk of researcher bias. Conducting phases I–III online had several strengths. It was easier to include participants across different geographical locations. The participants could contribute when it best suited them, enabling them to take necessary breaks. A downside of using GCM online is problems with attrition, as it can be challenging to ensure the participants complete all the phases. Especially phases II–III, as they were demanding and time-consuming to complete. In our study, this was probably the reason why approximately 50% of the participants from Phase I did not undertake phases II–III. However, this was not unexpected as a previous analysis of GCM studies found that a completion rate for sorting and rating of around 50% is normal (LaNoue et al., 2016). However, in GCM, the number of participants rating and sorting is not that important, the essential is that all major perspectives on the topic are represented in the rating and sorting (LaNoue et al., 2016). In our study, there were a variation in sex, life circumstances, types of cancer, disease status and professional background in the group of participants involved.

Another study limitation is the limited number of family and friends and no work-related stakeholders that may have brought additional perspectives on the topic. However, there are several ideas related to returning to work and support for family members and friends.

The results may not be generalizable to all YACS as most of the YACS were at the end of the age range (18–39 years) and were diagnosed with cancer over 2 years ago. Whether this influenced the ideas and rating of these is unclear. However, the identified intervention components like intervention components found in studies with YACS <25 years (Galán et al., 2017; Tsangaris et al., 2014). In the future, it would be interesting to conduct a longitudinal study with a larger sample, investigating how YACS' rehabilitation needs and preferences change during cancer survivorship.

In conclusion, this study found that rehabilitation for YACS should include intervention components within the following eight components, which were rated equally important: (1) Treatment and possibilities within the social and healthcare system, (2) Peer-to-peer, (3) Rights and Finance, (4) Education and Work, (5) Body and Everyday Life, (6) Psychological problems, (7) Sexuality and Relationships and (8) Family and Friends. Future research should build upon the knowledge generated from the present study to develop and test the feasibility of a rehabilitation intervention for YACS targeting their everyday life.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

AUTHOR CONTRIBUTIONS

The individual authors have contributed to Maria Aagesen: Overall planning with Marc Sampedro Pilegaard, Eva Elisabet Ejlersen Wæhrens, May Aasebø Hauken and Karen la Cour, all phases of data generation and analysis and writing all drafts of the paper. Marc Sampedro Pilegaard: Overall planning with Eva Elisabet Ejlersen Wæhrens, Karen la Cour, May Aasebø Hauken and Maria Aagesen, all phases of data generation and analysis and input to all drafts. May Aasebø Hauken: Overall planning with Marc Sampedro Pilegaard, Eva Elisabet Ejlersen Wæhrens, Karen la Cour, and Maria Aagesen and input of all drafts. Eva Elisabet Ejlersen Wæhrens: Overall planning with Marc Sampedro Pilegaard, Karen la Cour, May Aasebø Hauken and Maria Aagesen, all phases of data generation and analysis, and input to all drafts. Karen la Cour: Overall planning of the research project with Marc Sampedro Pilegaard, Eva Elisabet Ejlersen Wæhrens, May Aasebø Hauken and Maria Aagesen, most phases of data generation and analysis and input all drafts.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ORCID

Maria Aagesen https://orcid.org/0000-0002-0476-3692
Marc Sampedro Pilegaard https://orcid.org/0000-0001-6362-410X
Eva Elisabet Ejlersen Wæhrens https://orcid.org/0000-0002-0846-1659

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APPENDIX A

TABLE A1 Final eight clusters, included ideas and the rating of importance across participants for each idea and the median of the medians of the ideas within each cluster

		Median (range)		
Cluster names and included ideas		**Total (n = 26)**	**YACS/family (n = 11)**	**Professionals/representatives (n = 15)**
Treatment and possibilities within the social and healthcare system (n = 29)				
1	Better information about existing opportunities/services (e.g., groups, social worker and young cancer)	4 (3–5)	5 (4–5)	4 (3–5)
9	A coordinator to help with administration of practical issues throughout the spell of sickness, for example, appointments (hospital, study and municipality), economy, insurance and study	4 (2–5)	4 (3–5)	4 (2–5)
15	Better knowledge about late effects among general practitioners so they can act in relation to sick leave due to, for example, cognitive challenges, which can be difficult for them to explain to their general practitioners	4 (2–5)	4 (3–5)	4 (2–5)
22	Personal support—for example, telephone conversations as in 'active patient support'	4 (2–5)	3 (2–5)	4 (2–5)
37	A nurse contact person who you can contact after the period of cancer has ended	4 (2–5)	4 (2–5)	4 (2–5)
40	A conversation after diagnosis (maybe a couple of days after) to talk about existing opportunities after operations/chemo and so forth. is over	4 (2–5)	4 (2–5)	4 (3–5)
41	Gather information about services in one place	4 (2–5)	4 (3–5)	4 (2–5)
47	A contact person who follows up and keeps in touch	4 (1–5)	4 (1–5)	4 (3–5)
49	Rehabilitation stays in Denmark or abroad	4 (1–5)	4 (1–5)	4 (1–5)
51	Personal or individual guide instead of generic groups and services	3 (1–5)	4 (1–5)	3 (2–5)
65	Individual services based on the individual's needs (dietitian, social worker etc.)	4 (2–5)	4 (3–5)	4 (2–5)
66	Guidance on cancer and treatment	4 (2–5)	4 (3–5)	4 (2–5)
72	Assessment of young adults need for help. It should be assessed together with a professional with experience of the challenges young adults may have after cancer	4 (3–5)	4 (3–5)	4 (3–5)
77	Courses with 'young adult conversations' in the hospital	4 (1–5)	3 (1–5)	4 (2–5)
80	Easy access to professionals who may be needed: Sexologist, psychologist, dietitian, physiotherapist, social worker and so forth	**5 (3–5)**	4 (3–5)	5 (3–5)
88	Knowledge of rehabilitation services in the municipalities	4 (3–5)	4 (3–5)	4 (3–5)
89	Opportunity for continued contact with a youth coordinator at the hospital who knows the young adults with regard to, for example, young adult conversations' and guidance regarding late effects	4 (1–5)	4 (1–5)	4 (3–5)
92	Continued needs assessments for help at the appointments at the hospital	4 (2–5)	4 (2–4)	4 (2–5)
95	Courses with the purpose of receiving knowledge about their cancer	4 (1–5)	3 (1–4)	4 (3–5)
106	Help to be able to relate to being or becoming parents	4 (1–5)	4 (1–5)	4 (1–5)
110	Services in the municipality where the young adults live	4 (2–5)	4 (2–5)	4 (2–4)
119	Continuity in the healthcare professionals the young adults meet	4 (2–5)	4 (3–5)	4 (2–5)
123	Get affiliated with a youth counsellor	3 (2–5)	4 (3–5)	3 (2–4)
125	Young adults should meet healthcare professionals who have specific knowledge of young adults	4 (2–5)	4 (2–5)	4 (3–5)
130	Attention and treatment of late effects	5 (3–5)	5 (3–5)	5 (4–5)
132	Systematic involvement of cancer coordinators	4 (2–5)	3 (2–5)	4 (3–5)

TABLE A1   (Continued)

		Median (range)		
Cluster names and included ideas		Total (n = 26)	YACS/family (n = 11)	Professionals/representatives (n = 15)
134	Multidisciplinary team meetings based on structured young adult conversations, which are based on the young adults need/challenges/unresolved issues	4 (2–5)	3 (2–3)	4 (3–5)
138	Help with navigation of the healthcare system as young adults do not have the same experience with this, as older adults do	4 (2–5)	4 (2–5)	4 (2–5)
139	Youth friendly interior design in the hospitals	3 (1–5)	3 (1–5)	4 (2–5)
	Median of the medians of the ideas within the cluster	4 (3–5)	4 (3–5)	4 (3–5)
Rights and finance (n = 10)				
18	Help with economy. Insurance, grants and possible subsidies for residence, children or study	4 (1–5)	4 (1–5)	4 (2–5)
38	Guidance on insurance and pitfalls regarding cancer disease, for example, accident insurance/life insurance	4 (2–5)	4 (2–5)	4 (2–5)
46	Economic help with practicalities that can be difficult for a period, for example, cleaning	3 (2–5)	4 (2–5)	3 (2–5)
74	Knowledge about support measures during education, for example, part-time study, technical aids, rights, opportunities for support and other things	4 (2–5)	4 (2–5)	4 (3–5)
82	Help with practicalities	3 (2–5)	3 (2–5)	3 (1–4)
118	Knowledge about possibilities for help at home	4 (2–5)	4 (2–5)	3 (2–5)
127	Easy access to social workers in the municipality so the young adult does not need to be sent from one to another	4 (3–5)	4 (3–5)	5 (3–5)
137	Young adults must know their rights, for example, confidentiality, informed consent, possibilities to complain and so forth	4 (1–5)	4 (1–5)	4 (2–5)
142	Access to special educational support and thus a mentor as well as supplementary professional guidance	3 (2–5)	3 (2–5)	4 (2–5)
143	Social worker advice regarding notification of illness, rights and economy	4 (3–5)	4 (2–5)	4 (2–5)
	Median of the medians of the ideas within the cluster	4 (3–4)	4 (3–4)	4 (3–4)
Education and work (n = 18)				
10	Equip study counsellors to better deal with cancer patients with late effects	4 (2–5)	4 (2–5)	4 (2–5)
11	Possibility for a healthcare professional act as an advocate in connection with student guidance regarding the time perspective and late effects in relation to an individual's disease	4 (2–5)	4 (2–5)	4 (2–5)
17	Help to return to work	5 (2–5)	5 (4–5)	4 (2–5)
20	Support for return to work; how to handle it—Help with structure regarding number of hours	4 (2–5)	4 (3–5)	5 (2–5)
25	A type of intermediary between notification of illness and work—Maybe a re-entry possibility through the municipality or a 'phased return'	4 (2–5)	4 (3–5)	4 (2–5)
27	A reasonable job plan with a gradual escalation in number of hours and tasks, for example, with help from the municipality	4 (3–5)	4 (4–5)	4 (3–5)
28	Continuous dialogue with their manager	4 (2–5)	4 (2–4)	4 (2–5)
58	Help with returning to or starting in education	4 (3–5)	4 (3–5)	4 (3–5)
61	Opportunities for extension of or specially planned study options	4 (3–5)	4 (3–5)	4 (3–5)
64	Supportive conversations with social worker or student counsellor	4 (2–5)	3 (2–5)	4 (3–5)
69	Specialised student counselling	4 (2–5)	4 (2–5)	4 (2–5)
75	Cooperation between the cancer rehabilitation unit, the job centre and the employer	5 (3–5)	4 (3–5)	5 (3–5)
86	Support to apply for disability state educational grants as required	4 (1–5)	4 (2–5)	4 (1–5)

(Continues)

TABLE A1 (Continued)

Cluster names and included ideas		Median (range)		
		Total (n = 26)	YACS/family (n = 11)	Professionals/representatives (n = 15)
96	Prepare the place of study for the challenges that are associated with having cancer	4 (3–5)	4 (3–5)	4 (3–5)
105	Social worker advice in relation to returning to or remaining in education	4 (2–5)	4 (2–5)	5 (2–5)
112	Opportunity to be in close contact with the cancer rehabilitation when work resumes	4 (2–5)	4 (4–5)	4 (2–5)
114	Help to get 'it' told in school, to friends, so 'it' is not a taboo	4 (2–5)	4 (2–5)	4 (2–5)
141	Flexible study conditions	4 (2–5)	4 (2–5)	4 (2–5)
	Median of the medians of the ideas within the cluster	4 (4–5)	4 (3–5)	4 (4–5)
Psychological problems (n = 17)				
4	Conversational therapy with partners on the anxiety/fear of death implied by the cancer diagnosis	4 (3–5)	4 (3–5)	4 (3–5)
5	Individual conversational therapy for the anxiety/fear of death implied by the cancer diagnosis	5 (3–5)	5 (3–5)	4 (3–5)
26	A presentation by a psychologist/mentor who can prepare you mentally to return to work	4 (2–5)	4 (2–5)	4 (3–5)
30	Coaching in relation to accepting the news and new reaction patterns	3 (1–5)	4 (1–5)	3 (2–5)
43	Conversations with a psychologist	4 (2–5)	5 (3–5)	4 (2–5)
56	Help to maintain courage and zest for life during a difficult period	4 (3–5)	4 (4–5)	4 (3–5)
60	Offer of help with existential issues	4 (2–5)	4 (2–5)	4 (2–5)
67	Help with realisation of the situation via psychological support	4 (1–5)	4 (1–5)	4 (2–5)
76	Knowledge about loss of identity	4 (1–5)	4 (1–5)	4 (3–5)
81	Offer of help with psychological issues	5 (2–5)	5 (4–5)	4 (2–5)
84	Coaching regarding knowing own boundaries and reporting these realistically to the outside world	4 (2–5)	4 (3–5)	3 (2–5)
91	Psychological support regarding existential crisis	4 (3–5)	4 (3–5)	4 (3–5)
102	Work on 'who am I now'—Identity	4 (2–5)	4 (3–5)	4 (2–5)
108	Mental health services in relation to managing worries and thoughts about the future	4 (2–5)	4 (2–5)	4 (3–5)
115	Help to address anxiety and fear of recurrence	4 (3–5)	4 (4–5)	4 (3–5)
117	Help to dare to feel happiness	4 (2–5)	4 (3–5)	4 (2–5)
124	A place where you can vent, to get rid of anxiety to someone who is not counting on you and will be less anxious in the future	4 (2–5)	4 (2–5)	4 (3–5)
	Median of the medians of the ideas within the cluster	4 (3–5)	4 (4–5)	4 (3–4)
Body and everyday life (n = 30)				
2	Offer of meaningful physically based exercise	4 (1–5)	4 (1–5)	4 (3–5)
3	Offer of massage	2 (1–5)	2 (1–5)	2 (1–5)
7	Opportunities for physiotherapy to dare to relate to own body again through exercise or touch	4 (3–5)	4 (3–5)	4 (4–5)
13	After 'Krop og Kræft' or rehabilitation in the municipalities, there is a wish for help to continue in a normal fitness centre for the first couple of sessions until you feel secure with being in the fitness centre and has got a workout routine up and running according to a workout diary	3 (1–5)	3 (1–5)	3 (1–4)
16	Opportunities for brain training, concentration, coordination and focus	4 (2–5)	4 (2–5)	4 (3–5)
21	Targeted physically based exercise that fits the individual cancer	4 (2–5)	4 (2–5)	4 (2–5)
32	Help to maintain everyday life as best as possible during treatment	4 (3–5)	4 (3–5)	4 (3–5)
34	Physically based exercise group only for young adults	4 (2–5)	3 (2–5)	4 (2–5)

TABLE A1   (Continued)

Cluster names and included ideas	Median (range) Total (n = 26)	YACS/family (n = 11)	Professionals/representatives (n = 15)
39	A personal or group coach that can compose a simple physically based exercise scheme based on one's situation, possible surgeries and so forth, as that is often given as the first solution to get energy back	3 (2–5)	3 (2–5)	3 (2–5)
48	Obligatory, positive, supported physically based exercise	4 (2–5)	3 (2–5)	4 (2–5)
50	Managing their social lives when surplus energy runs out	4 (2–5)	4 (2–5)	4 (2–5)
52	Guidance on diet	4 (2–5)	4 (2–5)	4 (2–5)
55	Guidance on physically based exercise	4 (2–5)	4 (3–5)	4 (2–5)
57	Workshops about work-life balance after their life have changed	4 (1–5)	4 (1–5)	4 (2–5)
62	Knowledge about cognitive challenges	4 (2–5)	4 (2–5)	4 (3–5)
68	Physically based exercise offered with the opportunity to meet other young adults with cancer	4 (3–5)	4 (3–5)	4 (3–5)
70	Balance in everyday life based on the late effects suffered	4 (3–5)	4 (3–5)	4 (3–5)
71	Help for conversation of energy including prioritising activities in everyday life	4 (3–5)	4 (3–5)	4 (3–5)
83	Competence to manage cognitive challenges	4 (1–5)	4 (1–5)	4 (3–5)
94	Help and opportunities for guidance about bodily changes	4 (2–5)	4 (3–5)	4 (2–5)
98	Physically based exercise	4 (3–5)	4 (3–5)	4 (4–5)
99	Help with rehabilitation	5 (3–5)	5 (4–5)	5 (3–5)
101	Help to structure everyday life	4 (2–5)	3 (2–5)	4 (2–5)
103	Knowledge about energy conservation	4 (2–5)	3 (2–5)	4 (2–5)
109	Stress reducing services, for example, yoga, mindfulness and stress relief	4 (2–5)	4 (2–5)	4 (3–5)
116	Physical activity	4 (3–5)	4 (3–5)	5 (4–5)
145	Knowledge regarding the importance of starting physical activity again	4 (3–5)	4 (3–5)	4 (3–5)
146	Knowledge regarding the importance of starting socialise again	4 (1–5)	4 (1–5)	4 (3–5)
147	Workout buddy	3 (1–5)	2 (1–5)	3 (1–5)
148	Clubs with teammate who are interested in why you do not come to training and ask when you will return	3 (1–5)	3 (1–4)	3 (2–5)
	Median of the medians of the ideas within the cluster	4 (2–5)	4 (2–5)	4 (2–5)
Peer-to-peer (n = 29)				
6	Meeting like-minded people with cancer with the same type of cancer to not feel completely alone with late effects and the worries the type of cancer-type causes	4 (2–5)	4 (3–5)	4 (2–5)
8	Opportunities to meet other people of the same age	4 (2–5)	4 (2–5)	4 (3–5)
12	Opportunities for municipal/regional services with a view to meeting other young adult cancer survivors and healthcare professionals	4 (2–5)	4 (2–5)	4 (3–5)
19	Opportunities to meet other young people	4 (1–5)	4 (1–5)	4 (4–5)
23	Groups to talk with other young/younger adults with a cancer diagnosis	4 (2–5)	4 (3–5)	5 (2–5)
31	Focus on services for healthy young adults	3 (1–5)	3 (1–5)	3 (1–5)
33	A form of therapy or opportunity to talk to others in the same situation. However, not necessarily with someone who is worse affected than one is, as you can feel a little ashamed about your situation, when they feel much worse	3 (1–5)	3 (1–5)	3 (1–4)
45	Conversations with other young adults in the same occupational situation (job/education/in-between) in the returning to work phase	4 (1–5)	3 (1–5)	4 (2–5)
53	Opportunity to meet other young adults in the community	4 (2–5)	3 (2–5)	4 (2–5)
59	Opportunity to meet other young adults with cancer	4 (3–5)	4 (3–5)	5 (3–5)
63	To discuss dating and sex with other young adults	4 (1–5)	4 (1–5)	4 (2–5)

TABLE A1 (Continued)

		Median (range)		
Cluster names and included ideas		**Total** (n = 26)	**YACS/family** (n = 11)	**Professionals/representatives** (n = 15)
78	Communal eating	2 (1–5)	2 (1–5)	3 (1–5)
79	Networks with other young adults	4 (3–5)	4 (3–5)	4 (3–5)
85	Conversation with other people in the same age group	4 (3–5)	4 (3–5)	4 (3–5)
87	Common meeting place for those who are sick and their friends, classmates and colleagues, so the distance is shortened, and relationships are maintained	3 (1–5)	3 (2–5)	4 (1–5)
90	More voluntary services specifically for young adults	4 (2–5)	4 (3–5)	3 (2–5)
93	Peer-to-peer	4 (1–5)	3 (1–3)	4 (3–5)
97	Meeting place for young adult cancer patients	4 (3–5)	4 (3–5)	4 (3–5)
104	Possibility for communities of other young adults in the hospital setting with the opportunity to exchange experiences and knowledge and so forth facilitated by healthcare professionals. With a focus on youth and experiences that go beyond illness and treatment	4 (2–5)	4 (2–5)	4 (2–5)
111	Opportunity for municipality rehabilitation with peers	4 (3–5)	4 (3–5)	4 (3–5)
113	Events and opportunities for support of different kinds from patient associations	3 (2–5)	3 (2–5)	4 (2–5)
122	Youth communities outside hospital	4 (2–5)	4 (3–5)	4 (2–5)
128	Social interaction with other young adults with cancer	4 (3–5)	4 (2–5)	4 (3–5)
129	Movie club and book club	2 (1–4)	2 (1–4)	2 (1–3)
131	Courses about life (including sex life) with cancer from a young adults' perspective	4 (2–5)	3 (2–4)	4 (2–5)
133	Themed evenings about, for example, fertility, late effects, food when you are sick (and tired), medical cannabis and existential issues (guilt, shame, loneliness etc.)	4 (1–5)	4 (1–5)	4 (3–5)
135	Youth committee meetings—Where young adults set the agenda in hospital settings	3 (2–5)	3 (2–5)	4 (2–5)
144	Associations/groups that know something about cancer	4 (2–5)	4 (3–5)	3 (2–4)
149	Associations/groups that have the ability to embrace many different people with different kinds of challenges (physical, as well as mental and social)	3 (2–5)	3 (2–5)	3 (2–5)
	Median of the medians of the ideas within the cluster	4 (2–4)	4 (2–4)	4 (2–5)
Sexuality and relationships (n = 6)				
36	Opportunities for couples therapy with guidance and direction on getting as good as possible through the course of the disease	4 (2–5)	4 (4–5)	4 (2–5)
42	Help for relationship	4 (3–5)	4 (3–5)	4 (3–5)
44	Conversations with sexologist	4 (2–5)	4 (2–5)	4 (2–5)
73	Counselling about family life, roles and expectations for each other	4 (2–5)	4 (3–5)	4 (2–5)
100	Help with issues related to sexuality	4 (2–5)	4 (2–5)	4 (3–5)
120	Fertility guidance	4 (3–5)	4 (3–5)	4 (3–5)
	Median of the medians of the ideas within the cluster	4 (4)	4 (4)	4 (4)
Family and friends (n = 10)				
14	Concise information material for relatives, which the person with cancer can give to their relatives containing information about how to socialise with a cancer patient, help (both physically with cleaning, shopping, frozen food and companionship for hospital visits) and mental (just listening, offering for you to just rest and initiate small trips as, for example, small celebrations during the course of the disease, cinema, walks, café and games). Also, that the sick person has not necessarily recovered because the treatment has ended. Be	4 (2–5)	4 (2–5)	4 (3–5)

TABLE A1   (Continued)

	Cluster names and included ideas	Median (range)		
		Total (n = 26)	YACS/family (n = 11)	Professionals/representatives (n = 15)
	aware of which late effects can subsequently happen and show consideration for this			
24	Guidance and direction on how to talk with own children about terminal illness in an appropriate way	5 (3–5)	5 (4–5)	4 (3–5)
29	Help with talking with family	4 (3–5)	4 (3–5)	4 (3–5)
35	Common events with partners/parents. For example, common exercise-based training followed by dinner once a month. Important that it is outside of work hours	3 (1–5)	3 (1–5)	3 (2–5)
54	Conversation/psychological help for the whole family about what they have come through and the new chapter that awaits	5 (3–5)	5 (2–5)	4 (3–5)
107	Conversation/guidance regarding finding the way back and getting on the same wavelength with friends	4 (1–5)	3 (1–5)	4 (2–5)
121	Support for parents and siblings	4 (3–5)	4 (4–5)	4 (3–5)
126	Help to speak with children who are relatives	5 (2–5)	5 (4–5)	4 (2–5)
136	Special services for young adults with children	4 (2–5)	4 (3–5)	4 (2–5)
140	Network conversations, involvement of parents, partners, siblings, friends and so forth	4 (3–5)	5 (3–5)	4 (3–5)
	Median of the medians of the ideas within the cluster	4 (3–5)	4 (3–5)	4 (3–4)

Abbreviation: YACS, young adult cancer survivors.