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Exploring the support needs of young adult caregivers, their issues, and preferences towards a web-based tool: a mixed-method study

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Abstract

Background Young adult caregivers (YACs, aged 18–25) who take care of a loved one may juggle between caregiving responsibilities and other life areas such as education and social life, leading to an imbalance in their lives. The web-based tool ‘MantelzorgBalans’ aims to support informal caregivers (ICGs) in balancing caregiving tasks and activities in other life areas. However, this tool was designed to support ICGs of loved ones receiving palliative care and is not yet tailored to the needs of YACs. In order to do so, in this study we aim to explore (i) challenges and support needs of YACs in caregiving, (ii) their needs towards the content of the ‘MantelzorgBalans’ tool, and (iii) issues they encountered in using the tool and their preferences for adaptation of the tool.

Method We conducted semi-structured interviews and usability testing with 13 student YACs in the Netherlands. Within usability testing, we used three approaches: (i) a thinking-aloud approach (verbalizing thoughts while using the tool), (ii) a task-based performance approach (scoring task completion rate), and (iii) questionnaires. We used thematic analysis to synthesize the qualitative data. For the quantitative data, we calculated frequencies and mean scores.

Results Our findings suggest that the majority of YACs faced challenges in balancing caregiving with life areas such as education and social life. They needed support from healthcare professionals who could listen to them without judging them. With respect to the MantelzorgBalans tool, YACs needed more information on how to provide emotional support to their loved one and the emotional support that is available for them. In regards to the aesthetics, they preferred bright colours and more visuals in the tool. Overall, they were satisfied with the information presented in the tool, but they were neutral in their willingness to use it in the future.

Conclusion From this study, we learn that YACs may experience specific challenges and needs in general, and towards a web-based tool in specific. In the near future, it will be important to develop digital tools to support YACs that match their specific needs. This may enable healthcare professionals to offer targeted and personalized digital support to YACs in future.

Keywords Young adult caregivers, Challenges, Support needs, Digital tool, Usability, User experience

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Introduction

Young adult caregivers (YACs) are individuals aged 18–25 years who provide care or assistance to a loved one (e.g., parent, grandparent) living with a disability, chronic illness, mental illness, frailty, or substance abuse problems [1]. Young adults are in the critical transition period between adolescence and adulthood. They explore the possibilities in life and make enduring choices in different life areas, such as education, career, and relationships [2–4]. The transition period can be challenging particularly for YACs as compared to their peers, as they also have to integrate caregiving responsibilities into their daily activities [5–8].

YACs find it challenging to fulfil personal, social, and professional goals because of their care responsibilities [6, 9, 10]. For example, care responsibilities limit YACs' attendance and academic participation at college. They also experience a loss of personal time, opportunities to pursue their leisure activities, connection with their peers in college, or possibilities to maintain their relationships with friends and close ones [8, 10–13]. This may lead to a perceived imbalance in their lives, as they are unable to spend enough time in life areas important to them. The literature suggests that YACs perceive a lower balance in life and lower well-being as compared to young adults without care responsibilities (non-YACs) [6, 9, 13–16]. These previous findings suggest a need to support YACs in creating a balance in life and improving their well-being.

YACs rarely receive support in caregiving as society is insufficiently aware of the existence of YACs and their problems [1, 17]. Furthermore, there is limited literature focusing on the support needs of YACs [18]. What we know from the existing literature is that YACs need healthcare professionals to recognize them as caregivers, consider their needs seriously and help them in coping with the challenging caregiving situations [19–21]. YACs also expressed a need for information about the illness of their loved one. They often searched for information on the internet, but questioned the reliability of the information they found. They wish for a dedicated website that offers them practical advice about their caregiving situation and makes them feel acknowledged as a caregiver [19]. Another quantitative study conducted among YACs taking care of a person with a mental illness suggests that more than half of the participants felt that web-based support could improve their caregiving situation, but most of them had never used it [20]. These findings suggest that digital support may be a mean to support YACs in caregiving. However, considering the limited literature, there is a need to increase our understanding of the support needs YACs have in general and their needs towards digital support.

Since the last decade, a broad range of digital applications or tools has been developed to support informal caregivers (ICGs), such as websites providing information on caregiving, tools to remotely monitor the care recipient (CR), and online consultations with health care professionals [22–25]. Digital applications or tools providing support to ICGs in caregiving have found to be effective to reduce depression and improve the quality of life of ICGs [24, 26–29]. One existing web-based tool to support ICGs is MantelzorgBalans [30], a website co-developed by the University Medical Center Groningen, the Netherlands, with the aim to support Dutch-speaking caregivers in balancing caregiving and other life areas, specifically focusing on ICGs taking care of a loved one receiving palliative care. The tool provides information on, among others, support options for ICGs, contains four exercises to give ICGs' insight into their life balance and boundaries, and provides a diary section in which ICGs can reflect on their feelings. Since this tool focuses on balancing the tasks of ICGs and improving ICGs' well-being, it might be considered as a tool to support YACs as well. However, as this tool was designed for ICGs of loved ones receiving palliative care, it would be interesting to explore whether this tool could match the needs of YACs. Needs could be regarding, for example, the information presented in the tool (i.e., the content of the tool), or preferences regarding how the information is presented (i.e., the layout of the information).

We already know from the literature that young adults use digital tools differently and may have unique preferences towards these tools as compared to older adults [30–33]. Young adults have grown up in times of the internet and tend to use digital devices and the internet more than other age groups [34]. They often navigate through digital tools confidently and tend to engage in several tasks online in parallel. Consequently, they become prone to making more errors when using an interface [35]. They have specific preferences towards the visual appeal of a digital interface, where they find a simple design style and bright colours in a design more attractive than did older adults [36, 37]. In exploring whether the MantelzorgBalans tool could be adapted to meet the support needs of YACs, it becomes important to consider also the perceptions of YACs towards the MantelzorgBalans tool with respect to the ease of use, satisfaction with the tool, their overall experience of using the tool (user experience), their willingness to keep using the tool (intention of use), and the potential of the tool to change their behavior (persuasive potential).

In light of the limited literature on the support needs of YACs, the first aim of this study is to explore the challenges and support needs YACs experience in daily life. Secondly, we aim to explore whether a tool focussing on

balancing activities and increasing ICGs' well-being, the MantelzorgBalans tool, could be adapted for YACs by evaluating their needs towards the content of the tool. Thirdly, we aim to get insight in the preferences and issues YACs have towards the MantelzorgBalans tool and therefore we explore YACs' perception towards the ease of use, and the user experience, satisfaction, intention of use, and persuasive potential of the tool.

Method

Participants and recruitment

The participants were eligible to participate in the study if they were YACs in the age group of 18–25 years and were students at the university, university of applied sciences, or secondary vocational education, in the Netherlands. The participants were recruited either through an online recruiting platform named Prolific or through a survey study conducted by Dang, Looijmans, Lamura, Hagedoorn (unpublished observations) that aimed to understand the perceived life balance among student YACs. At the end of the survey, YACs could indicate whether they liked to be contacted for a usability study. In total, 33 participants agreed to be contacted for the usability study and received the study information and a consent form via email or the Prolific chat option. The adequate sample size was assured through the process of data saturation, where data was collected until no new information was discussed by the participants [38]. In total, 13 agreed to participate, of which eight participated in English and five in the Dutch language. The study was approved by the Central Ethics Review Board non-WMO studies of the University Medical Center Groningen (research register number: 202000623), The Netherlands. All methods were performed in accordance with the Declaration of Helsinki.

Study design

A mixed-method study design was employed. We conducted semi-structured interviews and usability testing, a method to evaluate a product by testing it with the actual users, who are in this study YACs. We used the interviews to explore the challenges and support needs of YACs. Within usability testing, we used three approaches: (i) a thinking-aloud approach [39], that is, YACs were asked to verbalize their thoughts while using the tool, (ii) a task-based performance approach [40], that is, YACs were asked to complete three tasks in the tool and we scored their task completion rate, and (iii) questionnaires. With the thinking-aloud approach, we explored whether the content of the tool met YACs' needs, how easy it was for them to use the tool (ease of use), and their overall experience (user experience). The

task-based performance approach was also used to gain insight in YACs' ease of using the tool, and the questionnaires gave insight into the satisfaction, user experience, intention of use, and the persuasive potential of the tool among YACs.

Procedure

Since the study was conducted during the COVID-19 pandemic, YACs were invited to a digital usability testing session using a licensed version of the Google Meet platform offered by the University of Groningen. The study was conducted by two researchers; one researcher moderated the session and the other researcher took notes. All sessions were audio and video recorded with the verbal consent of the YACs. The mean duration of the sessions was 92 min.

Each session was divided into two parts. The first part consisted of a semi-structured interview where YACs were asked questions about demographic and caregiving characteristics, and questions about their challenges, current support being used, support needs, and barriers in using online support in caregiving. In the second part, we conducted the usability testing on the MantelzorgBalans tool. The link to the MantelzorgBalans tool was shared with the YACs via the chat of the Google Meet platform. YACs were asked to open the link and share the screen of their system. First, they were asked to perform three tasks on the tool that covered the most important sections of the tool. These tasks were created by one researcher (SD) and later reviewed by two other researchers (AL, AB, LGP). The three tasks performed were to (i) complete an exercise on balancing different activities in life, (ii) create memories with loved ones by uploading a sample picture portraying an ICG with their loved one, and (iii) read an article that provided information on the support available for caregivers to help them in caregiving (see Fig. 1). The tasks were explained to the YACs one by one verbally and shared in Google Meet via chat. They were asked to verbalize their thoughts while performing the task (thinking-aloud approach). In case of any doubt, YACs referred to the task in the chat or consulted the researcher. For each task, researchers noted the task completion rate of the YACs for each task (task-based performance approach). After completion of each task, YACs were asked to verbally rate their experience using a satisfaction questionnaire (questionnaire approach). After finishing all three tasks, YACs were asked to explore the tool for 10 min. After exploring the tool, they were asked to fill out questionnaires on user experience, intention of use, and persuasive

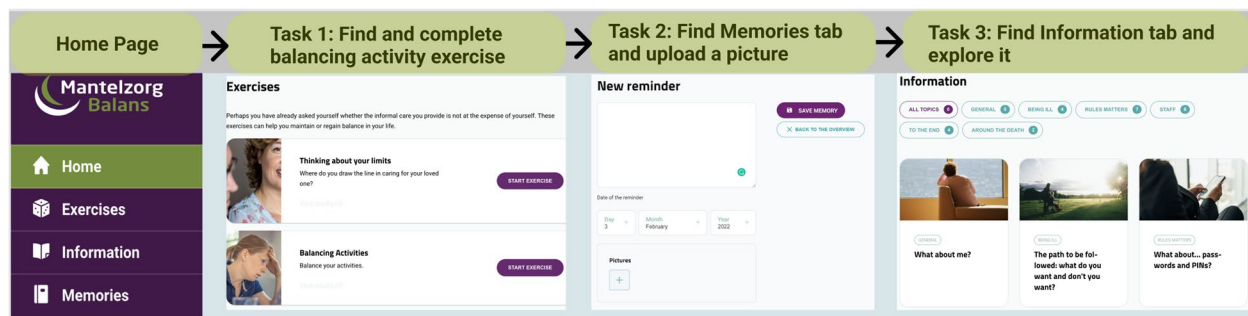


Fig. 1 Tasks performed by the participants (Source: <https://balans.mantelzorg.nl/>)

potential of the tool by sharing a Google form link over the Google Meet chat.

Measurements

Demographic and caregiving characteristics

Participants were asked to indicate their country of origin, who they cared for, type and severity of illness of the CR, duration of taking care, living status (i.e., whether they are living with the CR), anyone else providing care along with them and type of support provided to the CR.

Challenges and support needs

We used the interviews to gain insight into the challenges and support needs of YACs. Participants were asked questions on the challenges they experience in caregiving, on the support they currently use in caregiving, (*‘Are you aware of the support options that are currently available for you? If yes, do you currently use it (or have used it in the past?)’*), support they need (*‘What kind of support do you think could help you in caregiving?’*) and possible barriers in using online support (*‘What could be possible barriers for you to use online support?’*).

Needs towards the content of the tool

We explored YACs’ needs towards the content of the tool by using their verbalized thoughts while carrying out a task. We probed questions to gain more insights in the information shared by the YACs, for example, *‘Were you able to find the information you needed? If no, what information would you like to see here (in the tool)?’* We were interested in quotes on whether YACs felt that any information was missing and they would like to have it in a tool, or on information in the tool YACs liked and they considered helpful to them.

Ease of use

We assessed how easy it was for YACs to use the tool by the thinking-aloud and task-based performance approaches. For the thinking-aloud approach, we used

probing questions like *‘You missed noticing this (a particular) section, could you reflect on why this could have happened?’*. We gained insights in the ease of use by focusing on the issues encountered by YACs while carrying out the tasks (e.g., quotes that indicated any confusion or mistake) and, if any, their preferences for adaptation (e.g., quotes on suggestions, expectations or recommendations for improvement of the tool). We used the task-based performance approach to measure and categorize the task completion rate for all three tasks, which we categorized into three categories: (i) complete success: participant was able to complete the task without assistance, (ii) partial success: participant was able to complete the task with the help of the moderator, and (iii) failure: the participant thought the task was complete, but it was not or the participant gave up [41]. We calculated how many YACs were successful, partial successful, or failing in completing each task.

User experience

We assessed the user experience by using the thinking-aloud and questionnaire approach. For the thinking-aloud approach, we used probing questions like *‘Could you share your experience of completing this (a particular) task?’*. We were interested in quotes that represented YACs’ impression of the tool, such as whether they found the tool to be engaging or attractive.

The user experience questionnaire (UEQ) evaluated YACs’ overall experience of using the tool [42]. The original version of the user experience questionnaire was designed in German and English [42], but has so far been translated to several languages including Dutch. For this study we used the original English and Dutch version. The UEQ was used under Creative Commons Attribution licence (CC BY). The UEQ consists of 26 semantic differential items, that is, each item consists of a pair of terms with opposite meanings (e.g., annoying-enjoyable). It assesses the six main user experience attributes of the tool: attractiveness (appealing and pleasing), perspicuity

(ease of getting familiar), efficiency (use without unnecessary efforts), dependability (secure and predictable), stimulation (exciting and motivating to use), and novelty (creative and unique). The items were measured using a seven-point scale ranging from -3 to +3 between semantic differential items. For each user experience attribute, the mean score was calculated and interpreted as being a negative, neutral or positive impression based on cut-off values, where score between -0.80 to +0.80 is classified as neutral, >0.80 as positive and <-0.80 as negative user experience [42].

Satisfaction with the tool

Satisfaction with the tool was assessed using a three-item after scenario questionnaire (ASQ) evaluating the satisfaction towards ease of use, support information presented in the tool and amount of time spent in completing the task [43]. The original version of after scenario questionnaire was present in English language [43]. For this study we used the original English version and a translated Dutch version of the questionnaire. The ASQ was used under Creative Commons Attribution licence (CC BY). One additional question was added to examine the satisfaction towards the usefulness of the information presented in the tool. Thus, the scale consisted of four items using a five-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree). For each task, we calculated the mean score of the four items. A higher mean score indicates higher satisfaction for corresponding item.

Intention of use and persuasive potential

The persuasive potential questionnaire was used to evaluate the intention of use and persuasive potential of the tool [44]. The original version of the persuasive potential questionnaire was present in English language [44]. For this study we used the original English version and a translated Dutch version of the questionnaire. The questionnaire was used under Creative Commons Attribution licence (CC BY). The original questionnaire consists of five components, but considering the scope of this study, we only chose the components intention to use the system and general persuasive potential. The intention to use the system measures the motivation to keep using the tool, e.g., *'I have no motivation to use this tool'*, and general persuasive potential measures the general persuasive impact on the participants, e.g., *'The tool is useless for changing my behavior'*. Intention to use the system and general persuasive potential have 10 items each measured using a seven-point Likert scale ranging from 1 (completely disagree) to 7 (completely agree). We calculated the mean for intention to use the system and general persuasive potential where a higher mean score indicates a higher intention of use and more persuasive potential, respectively.

Data analysis

We used thematic analysis to synthesize the qualitative data from the interviews and thinking-aloud approach. All audio and video recordings were transcribed by a researcher (MW), and the Dutch transcripts were thereafter translated to English by ES and MM. Thematic analysis on all 13 English transcripts were conducted independently by two researchers, SD and NS, using Atlas.ti version 9. The researchers familiarized themselves with the data, by reading the transcripts line by line. Quotes were marked based on whether the data represented challenges, support needs in general, needs towards the content of the tool, issues encountered, preferences for adaptation or the overall impression of the tool. Following that, each researcher independently generated codes based on the quotes identified. Any discrepancies in identifying the codes were resolved with a detailed discussion between the researchers and codes were updated accordingly. When all data was coded, we used a mind map to group initial codes into main themes. Only codes that were mentioned by multiple participants were combined into themes. Two other researchers, MH and AL, checked the final themes, and any discrepancies were resolved with a detailed discussion between all researchers (SD, NS, MH, AL). For the quantitative data from the task-based performance and questionnaire approaches, we calculated frequencies to explore the ease of use and mean scores to explore the user experience, satisfaction with the tool, intention of use, and perceived persuasive potential of the MantelzorgBalans tool.

Results

Demographic and caregiving characteristics of YACs

A total of 13 YACs participated in the study (12 females; see Table 1). The age of the participants ranged from 19 to 25 years (mean age: 20 years). Most of the YACs were grandchildren and children to their care recipient (CR). Seven YACs were from the Netherlands and the other six were from Hungary, India, Indonesia, the Czech Republic, and the United Kingdom (2). Most of the YACs were not living with their CR, but were living alone or with friends. Five YACs were taking care since childhood, two since 6–8 years, and six since 1–3 years. YACs were mostly responsible for emotional support, such as listening to the CR, and household work, such as cooking.

Aim 1: Explore the challenges and support needs among YACs

Challenges faced in caregiving

Balancing caregiving with other activities During the interview, the most common challenge expressed by YACs was difficulty in finding a balance between caregiving and other activities in life such as studies and

Table 1 Demographic and caregiving characteristics of young adult caregivers

Participant number	Country of origin, language of the session	Whom they do take care	Type and severity of CR's illness	Duration of taking care	Living with the CR	Anybody else providing care	Type of support provided
P1	The Netherlands, Dutch	Younger sister	Autism and anorexia	Since childhood	No	Mother, aunt	- Practical support by carrying out the parenting duties if the parents are not around such as taking the younger sister to open days at school - Practical support such as cooking and cleaning for the CR - Emotional support such as listening and talking to her - Household tasks such as cooking and cleaning - Drive the CR to the hospital for the chemotherapies - Emotional support by listening and motivating the CR - Help with medicine - Picking up the CR from school - Assist in daily activities e.g., taking the CR out to cinema, getting him to bed - Assist in daily activities such as cooking for the CR, getting her dressed, giving her company - Household tasks such as cooking - Emotional support such as talking to the CR - Pick up medicines from the pharmacy and sometimes take the CR to the hospital
P2	The United Kingdom, English	Mother Grandmother Father	Burnout and trauma Frailty ^a Stage two of multiple myeloma	2 years b 1 year	No No Yes	Aunt Aunt Mother	
P3	Czech Republic, English	Boyfriend	Depression	1 year	Yes	No	
P4	The Netherlands, Dutch	Younger brother	Down syndrome	Since childhood	Yes	Parents and younger brother	
P5	The United Kingdom, English	Grandmother	Frailty Limited mobility	8 years	No	Parents and younger brother	
P6	The Netherlands, Dutch	Mother	Rheumatism ^a	2 years	No	Father	

Table 1 (continued)

Participant number	Country of origin, language of the session	Whom they do take care	Type and severity of CR's illness	Duration of taking care	Living with the CR	Anybody else providing care	Type of support provided
P7	The Netherlands, Dutch	Mother	Multiple sclerosis	Since childhood	No	Father and younger sister	<ul style="list-style-type: none"> - Help with bathing - Occasionally cook for the CR - Provide emotional support - Give the CR medicines that includes buying, sorting and arranging medicines as well
P8	India, English	Parents	Hereditary illness	For years	No	Brother	<ul style="list-style-type: none"> - Practical support such as taking care of household chores and reminding the CR about the hospital appointments
P9	The Netherlands, English	Grandmother	Frailty, osteoporosis and early stages of dementia	Since childhood	No	Mother, father and sister	<ul style="list-style-type: none"> - Emotional support such as talking to the CR on the phone 4-5 times a week - Practical support such as helping with the grocery shopping
P10	The Netherlands, English	Grandmother	Frailty	3 years	No	Mother and sister	<ul style="list-style-type: none"> - Household tasks such as cooking and cleaning the house for the CR
P11	Indonesia, English	Girlfriend	Mental illness: bipolar disorder but not clinically diagnosed	2 years	No	Therapist	<ul style="list-style-type: none"> - Emotional support such as motivating and guiding the CR - Financial support such as paying for therapies and medicine
P12	The Netherlands, English	Friend	Cystic fibrosis	Since childhood	No	Boyfriend, friends	<ul style="list-style-type: none"> - Emotional support such as talking to the CR on the phone daily - Visit the CR at the hospital
P13	The Netherlands, Dutch	Grandfather	Frailty. Decline in hearing and seeing abilities	3 years	No	Mother and aunt	<ul style="list-style-type: none"> - Emotional support such as listening to the CR - Practical support such as help with the grocery shopping

^a Information about the severity of illness of the CR is missing

^b Information about duration of taking care missing

socializing with friends. Studies were compromised the most, as YACs found it hard to concentrate while taking care of the CR. They ended up spending long hours in caregiving and had to catch up with their studies late at night. *“It is hard to find a balance between how much time you spend on caregiving, how much time you spend on your study or sport or with friends because you can always do more for your loved one”* (P1, caring for younger sister having autism and anorexia).

Emotionally draining Most often YACs were not living with the CR and were taking care over the phone. Sometimes when the CR was not responsive over the phone, YACs worried about the well-being of the CR, making it emotionally draining for them. When YACs were living with the CR, they were providing extensive hours in caregiving and felt that caregiving is always there and consumes their energies.

Dealing with the behavior of the CR YACs found it challenging to deal with the behavior of the CR. In some cases, the CR did not want sympathy, making it difficult for YACs to find a balance between helping their CR and leaving the CR on their own. *“She doesn’t like to be felt sorry for, therefore, sometimes it’s hard to distinguish, when and how much should I push her? And maybe I should just let her do her own things?”* (P12, caring for a friend having cystic fibrosis).

Support needs in caregiving

Current use of support Most of the YACs did not receive any support in general and none were using any specific online caregiving application or tool to help them with caregiving. Some because they did not need support as things were going fine in caregiving, others mentioned that they were not aware of the available support because nobody informed them or they did not have time to skim through the internet to find support in caregiving. A few YACs asked their family and friends to support them with practical help such as doing groceries for their CR. A few YACs mentioned that they currently or in the past have received professional support, for example, by joining a caregiving organization or a peer support group. In addition, a handful of the YACs were also using an inbuilt phone application, such as an agenda application, to help them in caregiving by creating a list of tasks or reminding them to call the CR.

Support needed YACs indicated that they needed information about the illness of their CR, resources to help them in caregiving, like help with household tasks and

how to take care of their own wellbeing by reserving personal time. They also needed support from professionals who were trained in their field and who could listen to them without judging them, for example, support from a care organization. Moreover, few YACs needed help with practical tasks such as getting groceries or cleaning for their CR.

Willingness to use online support When asked about their willingness to use online support, most of the YACs were interested and happy to use it. They felt that through online support, they would be able to monitor the CR better as most often they did not live with the CR. Few YACs were not sure about using online support in the future. They believed it would depend on the kind of online support provided, and they indicated that they would be interested if the support is (i) focusing on emotional support, (ii) from people they know, (iii) provided by professionals, and (iv) hybrid support, that is, if they also get a chance to meet people in person.

Aim 2: Explore YACs’ needs towards the content of the tool During the thinking-aloud approach, YACs indicated three needs towards the content of the MantelzorgBalans tool, which are described below.

Information on mental health assistance and education

YACs preferred more information regarding mental health support on two topics, (i) professional mental health support available to them and their CR, and (ii) more focused tips or solutions in providing emotional support to their CR. *“I know that she (the CR) gets physical care from the hospital. So for young people like me who mostly provide mental support, I don’t see anything about mental health support”* (P12, caring for a friend with cystic fibrosis). In addition, they preferred information regarding support they could get from their university. Few ICGs who were taking care of either their sibling or a friend, also needed information regarding possible study options or courses available for the ill CR.

Examples and quotes from other ICGs

In general, YACs found the supportive examples in the tasks very helpful in interpreting and understanding the information presented in the tool. For example, in Task 1 (see Fig. 2, screen 14–21), YACs were asked to make a plan for ‘balancing caregiving with other activities’ by answering eight questions. Few YACs had difficulty in interpreting the questions, but they mentioned that the example answers below these questions were helpful in answering them. In addition, they found the quotes from other ICGs depicting their life experiences motivating.

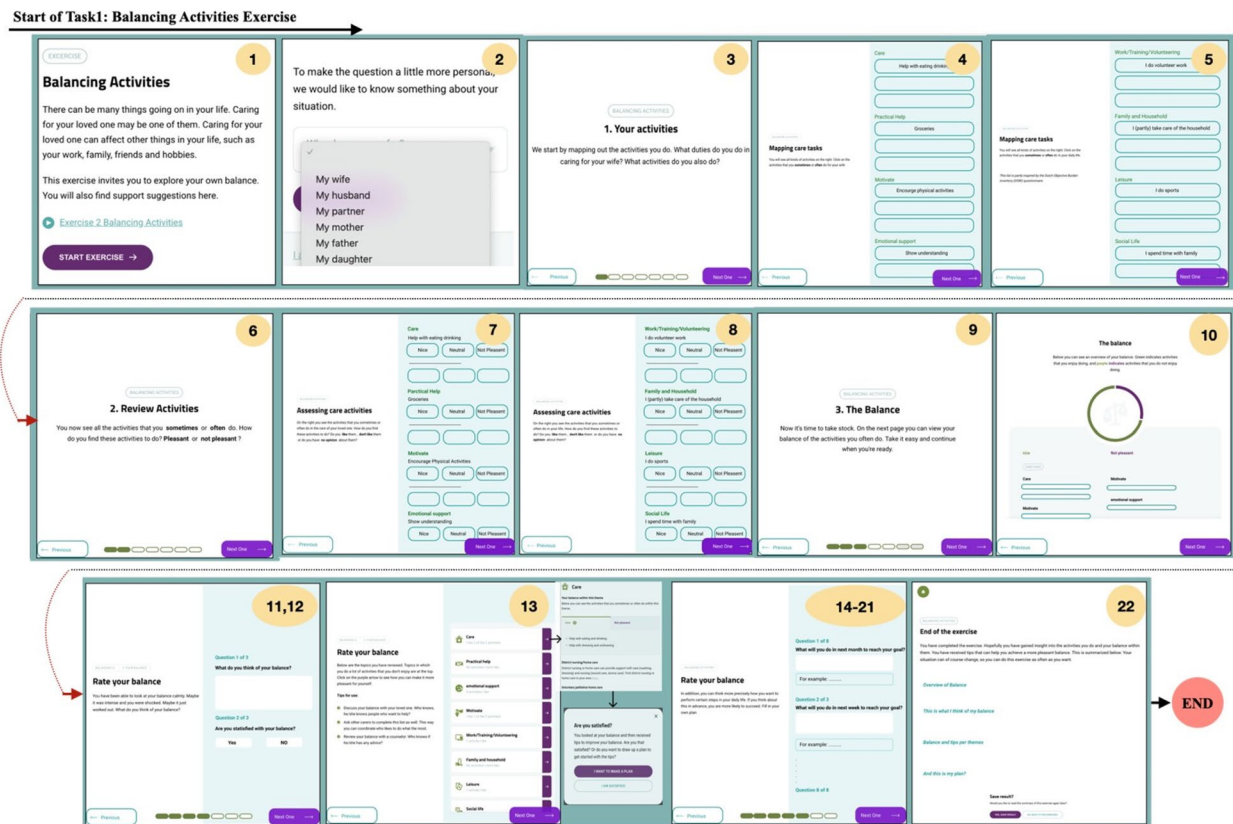


Fig. 2 Workflow for Task 1 representing 22 screens

However, these quotes were from older ICGs and YACs preferred quotes from ICGs in their age group as they would relate more to their experiences. *“If it’s really a website for young caregivers you don’t expect a quote from someone who is 49 years old” (P4, caring for a younger brother with Down syndrome).*

Aim 3: Explore YACs’ perception towards the ease of use, user experience, satisfaction, intention of use, and persuasive potential of the tool

We first describe YACs’ perception towards the ease of use and the user experience presenting the qualitative data from the thinking-aloud approach, followed by the quantitative data from the task-based performance approach. Finally, we present the quantitative data from questionnaire for satisfaction, intention of use, and persuasive potential of the tool.

Ease of use

Issues with scrolling the page for more information During the thinking-aloud approach, YACs did not notice that they could scroll down the page to find more

information and they preferred that all information would fit in one screen. They suggested a dropdown menu of main categories, in which participants can select specific categories to read more information instead of scrolling down the whole page.

Hyperlinks to additional information In Task 3, YACs were asked to explore the information section of the ‘MantelzorgBalans’ tool. YACs indicated that the articles were short and concise to read, and they found the hyperlinks referring to external information sources about the topic in case they required more information, useful.

Better representation of content When YACs were completing Task 1, in which they had to complete an exercise on balancing activities, they preferred to see information that was most relevant to them. For example, by presenting important information at the top of the page or they wanted information to be customized based on options they selected on the previous pages in the exercise. *“I think showing the solutions for just what I selected on the previous page would give a more personalized approach” (P8, ICG to parents with hereditary illness).*

Successful completion of the tasks During the task-based performance approach, ten out of 13 YACs successfully completed Task 1, all 13 successfully completed Task 2, and 12/13 YACs successfully completed Task 3 (Fig. 1). The other YACs were partially successful as the researcher (SD) needed to probe to complete the task correctly. For Task 1, one YAC had difficulty in identifying the task as she was looking for a questionnaire instead of an exercise in the tool to help her balance caregiving and other activities, and two participants (P1, P7) navigated to the information section instead of exercise section as they felt they would get an insight of their balance there. One participant, who partially succeeded in completing Task 3, landed on a different article and could not find the mentioned article until probed and helped by the researcher. Overall, most of the YACs could easily navigate through the tool and understand the information presented.

User experience

More visuals, less text During the thinking-aloud approach, YACs found the tool less attractive in terms of colors and experienced the tool as text-heavy. Therefore, they did not feel motivated to read all the information, and they preferred to have more visuals than text. YACs expressed that the tool could be made more attractive by using vibrant colors as they felt that it is designed for older people.

Positive experience in using the tool From the questionnaire approach, the mean score for all the user experience attributes (means range between 1.14–1.64), except novelty, were rated as positive, and novelty was rated as neutral ($M=0.77$), based on mean score cut-offs [42]. The moderately high scores for most of the user experience attributes indicate an overall positive user experience.

Satisfaction in using the tool, intention of use and persuasive potential

From the questionnaire approach, the ASQ mean scores per item for each task ranged between 4.0–4.8 on a scale of 1 to 5. Thus, indicating that overall YACs were satisfied with the ease of use, the support information presented in the tool, and the amount of time spent in completing each task. Mean scores for the intention to use the system ($M=3.6$, $SD=1.6$) was slightly above average and for general persuasive potential ($M=4.3$, $SD=1.5$) was above average on a range of one to seven, indicating that although YACs felt that the MantelzorgBalans tool has the potential to influence their behavior, they were neutral in their willingness to use this tool in future.

Discussion

In this study, we explored (1) the challenges and support needs of YACs in caregiving, (2) their needs towards the content of a web-based tool ‘MantelzorgBalans’, and (3) the issues YACs encountered in using the tool and their preferences for adaptation of the tool. The results suggest that most YACs faced challenges in balancing their care responsibilities with other life areas (e.g., education, social life). YACs indicated that they needed information about the illness of their CR, and wanted support from healthcare professionals and their social network to help them in caregiving. In reviewing the MantelzorgBalans tool, most YACs wanted information on providing emotional support to their CR and on the emotional support that is available for the YACs themselves. They experienced some issues in navigation, as they missed scrolling down on a few pages to read more information. In regards to aesthetics of the tool, they did not find it to be very novel and preferred more lively colours and visuals in the tool. On the other hand, they did find the tool easy to use and were satisfied with the information presented in the tool. They also found the hyperlinks in the tool useful for reading additional information. Overall, they found the tool to be persuasive, but they were neutral in their willingness to use it in the future.

To our knowledge, this is the first study to conduct a usability study with YACs for gaining insight into their needs, issues, and preferences towards a digital tool. Considering that young adults are extensive users of digital tools and may use it differently than users of other age groups, it was important to involve YACs (end-users) in identifying their unique needs towards a digital tool. Various studies have demonstrated the relevance of involving end-users to design digital interventions [45–47]. For instance, a recent mixed-method study indicated that ICGs are likely to discontinue using a digital intervention if they did not perceive its features to be user-friendly. Therefore, focusing on ICGs’ needs during the development process is a critical aspect for the acceptability and adoption of digital interventions [48].

Principal findings

The most common challenge expressed by YACs was difficulty to balance caregiving with other life areas. This finding is consistent with the literature [49, 50] and can be explained by highlighting the critical development phase of young adults. In this phase, young adults move towards leading an independent life away from their family. Many choices and life paths become open to them as they are no longer under the supervision of their parents [51, 52]. However, young adults with care responsibilities (YACs) are required to invest time and energy

in caregiving as well. This may create an overload of demands in different life areas among YACs and increase their risk of negative psychological outcomes, such as depression and anxiety. Thus, there is a need for health-care professionals to be aware of these challenges and support YACs in prioritizing their responsibilities and creating more balance in their lives.

In regards to the 'MantelzorgBalans' tool, YACs needed information on providing emotional support to their CR and the emotional support that is available for them. This could be explained by YACs' living status, where in line with the literature [9], our results suggest that the majority of the YACs provide care at a distance over the phone (see Table 1). Caring at a distance may require them to provide more emotional support to their CR than physical support (e.g., bathing, toileting) as it makes it difficult for them to offer this type of support. Moreover, not living with the CR may generate a feeling of worry and insecurity regarding the well-being of their loved one. It may also evoke feelings of guilt about not being physically present to fulfil the moral responsibility of caring, creating an emotional burden on them. Thus, it becomes important to provide digital support to YACs that could help them in providing emotional support at a distance and dealing with their own emotional burden. Care at a distance, also indicated as emotio-spatial distance (i.e., the impact of spatial distance on the emotional response) in informal care, is being recently studied in caregiving research [53, 54]. However, despite of the fact that the majority of YACs may provide care at a distance, this topic has not yet been explored in the context of YACs. Future research may focus on studying how spatial distance shapes YACs' emotional responses to caring.

With respect to the ease of using the tool, YACs missed scrolling down a few pages in the tool. Research suggests that YACs tend to multitask with different technology devices (e.g., smartphone, laptop) and are surrounded by a lot of information on the internet, both relevant and irrelevant. This may lead to distraction and a diminished attention span among young adults [55, 56]. As a result, young adults may prefer to navigate through information that is easy to scan. YACs also liked hyperlinks to support the primary information available in the tool. Literature suggests that young adults are sceptical of the quality of health-related information presented online [57, 58]. They may need additional resources to verify the information presented to them online. It might be the case that hyperlinks can help YACs reach the source for the information available in the tool. Our findings suggest the need reduce their sceptical attitude by presenting relevant information supported with validated hyperlinks and references to the presented information.

Interestingly, YACs did not find the tool to be novel (creative and unique) despite using it for the first time. Moreover, in line with young adult literature [59, 60], our results suggest that they needed the tool to have bright colours and preferred more images and videos instead of reading text. It is seen that young adults are extensive users of digital applications on a daily basis [34, 61]. They may have experienced using similar kinds of websites in the past in terms of the design of the tool, and therefore, they may not have experienced the tool to be novel. Moreover, young adults are actively involved on social media platforms (e.g., Instagram), which primarily use images and videos as a medium to communicate. They may be more used to consuming information via visuals than text. Consistent with other research among young adults, through this usability study we learned that if we want to grab YACs' attention and harness the potential of a digital tool for improving their well-being, we need to include relevant and validated information presented using graphics and interactive designs.

Strengths and limitations

This study includes some important strengths. There is limited literature on the challenges and support needs among YACs. Our findings are a valuable addition to the literature to provide insight into the support needs in general, and needs, issues and preferences towards a web-based tool of YACs. Moreover, to achieve comprehensive insights into the three aims of our study, we designed a mixed-method study combining interviews with usability testing, including a thinking-aloud, task-based performance, and questionnaire approach. The quantitative data helped in enriching the findings of the qualitative data by adding depth to fully understand the perceptions of YACs towards the web-based tool.

It is important to highlight certain limitations that could have hampered the interpretation of the results. 12 out of 13 participants in our study were females, which can limit the generalizability of our results as female and male ICGs may experience caregiving differently [62, 63]. Literature suggests that female ICGs are more likely than male ICGs to experience caregiving burden and issues with mental health, such as depression [62, 64, 65]. Our results showed that YACs expressed a need for information on emotional support available for them. Due to the low number of males in our study, our results may lack the caregiving issues and support needs in caregiving experienced by male ICGs. Thus, a more balanced male and female sample size is needed in future studies for better understanding of caregiving experiences and support needs of both male and female ICGs. Furthermore, the study was conducted using an example web-based tool, MantelzorgBalans. Thus, some of our findings may be

specific to the MantelzorgBalans tool and it may therefore not be directly applicable to other web-based tools that will be designed for the YACs. However, healthcare professionals or designers of digital tools to support YACs may use our results focusing on the needs towards the content of the tool and preferences of YACs towards the navigation and aesthetics of MantelzorgBalans tool as design guidelines. In addition, MantelzorgBalans tool is only available in the Dutch language. We used the Google translator to conduct the study sessions in English. Although a large part of the translation was appropriate and correct, the translation was not optimal. This may have influenced our English participants' perception of the tool and in turn our results. Also, the persuasive potential questionnaire to assess the intention of use and persuasive potential of the tool, and after scenario questionnaire (ASQ) questionnaire to assess the satisfaction towards using the tool was not validated for the Dutch language. However, these questionnaires were translated in Dutch by a native speaker who has good knowledge of both the languages (English and Dutch) to have a good translated Dutch version of the questionnaires. The study sessions with the participants were around 1.5 h long, which may have led to some fatigue and perhaps disinterest among our participants influencing our data quality. However, to help them to stay focused, the participants were asked to take a break of 5–10 min in between the session if they wished to.

Conclusion and future implications

In this study, we described the results of semi-structured interviews addressing the challenges and support needs of YACs in general. We also conducted usability testing with YACs using an existing web-based tool, Mantelzorg-Balans, which was designed to support ICGs of CR who received palliative care. We explored whether this tool could also support the needs of YACs and what additional needs, issues and preferences they have towards this tool. Our results suggest that majority of YACs faced a challenge in balancing caregiving with other life activities. They needed supportive care from professionals and social support from their friends and family. With respect to the MantelzorgBalans tool, YACs needed more information on how to provide emotional support to their CR and the emotional support that is available for them. Moreover, they preferred bright colours and more visuals in the tool. Overall, they found the tool easy to use and were satisfied with the information presented in the tool, but they were neutral in their willingness to use it in the future. This study highlights that YACs may experience specific challenges and needs in general, and towards a digital tool in specific. Moving forward, it would be beneficial to have a more comprehensive understanding of

what research is needed to develop better tailored tools for YACs. From our results, it appears that the YACs primarily need emotional support from healthcare professionals including care organization and practical support from family and friends. Thus, for future research, it would be important to consider to involve a wider range of stakeholders (including care organizations) to design a more interactive digital tool that has a better fit with the users' needs and preferences. This may enable healthcare professionals to offer more targeted and personalized digital support to YACs in future.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s44247-023-00057-6>.

Additional file 1.

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Authors' contributions

All authors have contributed to the following: Study design: SD, AL, AB, MH; data collection: SD; data analysis: SD, NS, AL, MH; manuscript preparation: SD, NS, AL, MH, and critical review of the manuscript: AL, NS, AB, MH. All authors approved the final manuscript.

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Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The study was approved by the Central Ethics Review Board non-WMO studies of the University Medical Center Groningen (research register number: 202000623), The Netherlands. All participants provided their informed consent to participate in this study. The authors declare that the procedures were followed according to the regulations established by the University Medical Center Groningen ethics committee and to the Helsinki declaration of the World Medical Association.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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