

Original Article

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Web-based support for spouses of patients with life-threatening illness cared for in specialized home care – A feasibility study

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Abstract

Objectives. Psychoeducational interventions for family caregivers have shown to be effective but not possible for all caregivers to attend; thus, web-based interventions may be a complement. This study aimed to evaluate feasibility of a web-based intervention, “narstaende.se,” from the perspective of spouses of patients receiving specialized home care.

Methods. A website was developed, containing videos with conversations between health-care professionals and family caregivers (actors), informative texts, links to further information, and a chat forum. The aim of the website is to provide support and promote preparedness for caregiving and death, and the content is theoretically and empirically grounded. The study had a descriptive cross-sectional design. Altogether, 26 spouses answered a questionnaire, before accessing the website, and 4 weeks after this, 12 spouses were interviewed. Descriptive statistics and qualitative content analysis were used.

Results. Spouses experienced the website as being easy to use, welcoming, and with relevant content. Participating spouses would recommend “narstaende.se” to others in similar situations, and the majority found the website introduced timely. Videos seemed easily accessible and were most used, contributing to a feeling of recognition and sharing the situation. The online format was perceived as flexible, but still not all spouses visited the website, stating the desire for support in real life.

Significance of results. A web-based intervention can be feasible for spouses in specialized home care; however, the digital format is not suitable for everyone. Further research is needed to determine the website's potential to provide support and increase preparedness for family caregivers in general.

Introduction

Despite the worldwide expanding development of palliative care services (Clark et al. 2020), family caregivers often become the main caregiver and source of support to people with life-threatening illness receiving care at home (Pitceathly and Maguire 2003; Rowland et al. 2017). Being a family caregiver may bring positive perspectives such as feelings of reward, meaningfulness, and a deeper bond with the ill person (Henriksson and Arestedt 2013; Hovland and Mallett 2021). However, while they take on great responsibility, family caregivers also report requiring information, social and practical support (Aoun et al. 2013; Harding et al. 2012), support in coping and self-care (Arias Rojas and Garcia-Vivar 2015; Barker et al. 2017), as well as support in preparing for death (Barker et al. 2017). It has been shown that family caregivers put their own lives on hold and are less likely to pay attention to and care for their own health, often resulting in increased risk for somatic symptoms, anxiety, depression, and work-related and financial problem (Aoun et al. 2013; Harris et al. 2018; Hudson et al. 2011), as well as social isolation (Harris et al. 2018; Hudson et al. 2011). Among family caregivers, spouses often take the overall responsibility, providing more care with higher psychological and physical burdens (Pinquart and Sorensen 2011).

Systematic reviews (Ahn et al. 2020; Bilgin and Ozdemir 2022) have shown that interventions delivered in real life (IRL) can promote preparedness while improving the well-being of the family caregiver, as well as of the patient (Norinder et al. 2017). IRL interventions might, however, not appeal to all family caregivers, and although health-care professionals find participating

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rewarding, this can be difficult, both logistically and financially, to prioritize (Holm et al. 2015a). An alternative might be web-based interventions, with the advantage of availability without time and geographic barriers. Systematic reviews (Ploeg et al. 2018, 2017; Shin et al. 2018) report on a range of web-based intervention designs: online support groups, informational websites, and websites combined with telephone or e-mail support or with caregiver interactions online. The majority have targeted family caregivers of patients diagnosed with dementia, stroke, or newly diagnosed cancer, with good results.

A recent review by Finucane et al. (2021) suggests that digital interventions can be acceptable also to seriously ill patients and their caregivers. However, there is a lack of evidence-based digital resources focusing on the needs of family caregivers in palliative care (Scott et al. 2019).

As IRL interventions may not appeal to all or may not be possible to attend, especially for family caregivers of patients with palliative care needs, where support is crucial, it is imperative to further design, test, and evaluate web-based interventions in the palliative care context.

Aim

The aim of this study was to evaluate feasibility in terms of usability and acceptability of a web-based intervention “narstaende.se,” from the perspective of spouses of patients with life-threatening illness receiving specialized home care.

Methods

Intervention framework

The website, “narstaende.se” (in English “family caregiver.com”), is designed and developed in collaboration with health-care researchers, clinical health-care professionals, information systems researchers, a digital communication strategist, and an IT consultant and is accessible via cell phone, computer, or tablet. The content is evidence-based (Hauksdottir et al. 2010, 2013; Henriksson et al. 2013; Holm et al. 2016, 2015a; Valdimarsdottir et al. 2003) and theoretically grounded by the framework of Andershed and Ternstedt (2001) covering family caregivers’ principal needs “knowing, being and doing.” *Knowing* is a prerequisite for *being* and *doing* and covers the need for information, while *being* covers emotional and existential aspects and *doing* represents practical caregiver tasks.

The website is organized into 3 main domains: “Support to you – being a family caregiver,” “how to give support,” and “talk about it,” covering topics such as practical and medical issues, communication, and considerations for the future. At “narstaende.se,” the spouse accesses prerecorded videos, informative texts, an unmoderated, participant-driven chat forum, and links to further information. Altogether, there are 23 videos lasting between 2.5 and 8.5 min (on average 4.50 min) introduced with a short text about the content. In the videos, family caregivers, one man and one woman (actors), meet health-care professionals (authentic), talking about practical and emotional issues often raised by family caregivers (Table 1). The informative texts add information and complement the videos (Table 2). Also included are web links from official nonprofit websites with information, for example, about children, diagnoses, funerals, and applicable parts of the Swedish social insurance system. According to General Data Protection

Regulation (EU 2016/679), interaction on the page and user credentials are encrypted and secured.

Design

This study has a descriptive cross-sectional design combining data from questionnaires and interviews. Ethical approval was received by the Regional Ethics Board/Committee of Stockholm/ Swedish Ethical Review Authority 2018/1893-31; 2019-02242; 2021-00235. The study is registered on clinical trials.com (NCT03676283).

Inclusion criteria

Only cohabiting spouses were included in the present study, as they most often take on the overall caregiving responsibility and thus were expected to have adequate experiences to evaluate the website. Inclusion criteria were being a spouse (>18 years) to a person (>18 years) cared for in specialized home care due to any kind of life-threatening illness with palliative care needs. The spouse should be able to speak and understand Swedish.

Context and procedure

Five specialized home-care services in Stockholm, Sweden, participated in the recruitment for the study. The services deliver 24-hour care in private homes and are staffed by multidisciplinary teams, including nurses, physicians, physiotherapists, occupational therapists, dieticians, and social workers. Initially, the patient was approached by a health-care professional, providing written and oral information about the study. Due to the Covid-19 pandemic, the home-care services were under great strain and could not take active part in the recruitment. With approval from the regional ethics committee, the first author, who also has a clinical position, was granted access to the patients’ medical records by the director of each service to identify patients. An information letter was sent by post asking for permission to contact the spouse, followed by a text message to set up a suitable time for a phone call, about a week later. If the spouse agreed to participate during the phone call, instructions for registration were sent via e-mail and a study-specific code was sent by text message. Upon registration at “narstaende.se,” the spouse could again access information about the study and give informed consent. Two weeks after the contact, a text message was sent, asking whether the spouse had any questions about the log-in procedure, and if wanted, the researcher provided instructions to help in accessing the website.

Data collection and study variables

Recruitment to the study was open from October 2019 to December 2021, and data were collected through questionnaires and interviews.

Questionnaires

Data were collected using study-specific questionnaires at baseline and at follow-up 4 weeks later. The questionnaire, developed based on earlier studies (Hauksdottir et al. 2010; Henriksson et al. 2015; Valdimarsdottir et al. 2004), was sent electronically or, upon request, by post. The questionnaire included, for example, background variables such as age, gender, education, and single-item questions about the use of the website, structure, content, and timing.

Table 1. An overview of the videos presented in the domains on the website

<i>Support for you – being a family caregiver</i>
Breathing exercise
A breathing exercise, highlighting the importance of finding time for rest and recovery. (6:22)
Continue working or not
Common thoughts about continuing working or being more at home spending time together (3:32)
Finding energy
Reflections about what might contribute energy and strength. (5:34)
May I be happy
Accepting/allowing the conflicting feelings, also moments of being happy when a close person is seriously ill or has recently died. (4:20)
Being me
The importance of having moments to be alone or meet with others. (4:11)
Meeting others
Reflections on how relationships with others can change when someone is seriously ill. (2:41)
When death is closing in
Signs and symptoms that might indicate that life is coming to an end and possibilities for symptom relief. (8:37)
Many different emotions
Self-care and acceptance, how to take care of oneself, and that it is okay to feel the perhaps conflicting emotions one feels. (4:23)
The loss
Reflections on common thoughts and feelings after the death of a close person and if one can say that “time heals all wounds.” (3:18)
<i>How to give support</i>
Relieve the bad and find the good
Common symptoms that may need to be medically alleviated and side effects are described. (08:10)
Appetite loss
About appetite loss and the challenges of discomfort and nausea from smells or when seeing food. Strategies that can be used around mealtimes. (3:07)
Nutrition and weight
Advice on coping with eating difficulties and weight loss as well as discussions about risks for potential side effects with artificial nutrition near end of life. (4:29)
Little helpful things
Reflections about how to plan activities and contribute to reduced pain through massage. (5:52)
Pain relief
Nearly all symptoms can be relieved. A discussion about the importance of pain relief and concerns about side effects and fear of addiction. (5:50)
Thoughts when terminating active illness treatment
If the person who is ill has chosen to withdraw from active illness treatment, feelings may arise about hope being lost and death is closing in. (5:41)

(Continued)

Table 1. (Continued.)

<i>Talk about it</i>
Ask for help
About the often unusual situation of being in need of help and support and about people around being supportive or withdrawn. (5:41)
Funeral/memorial ceremonies
Conversation about how funeral/memorial ceremonies can be meaningful in processing the situation. (3:38)
Concerns about the future
Comfort of sharing thoughts and worries, preparing for the time that will come after a close person has died. (5:20)
Being a family member and a family caregiver
Reflections on shifting roles and degrees of integrity are addressed as well as how to apply for help from home service. (3:11)
Talk about dying
About anxiety and different feelings as well as conflicting thoughts that may arise before death, talking about emotions is acknowledged. (4:03)
Nice to have talked about
With limited time left, sharing memories of joy and sorrow through life might inspire to think through what one would want to say while there is still time. (4:27)
Withdrawal of treatment
As death approaches, treatment of the disease may have more side effects and perhaps quality of life is improved focusing on symptom-relieving care. (5:39)

Interviews

To learn from spouses’ experiences of using the website and deepen understanding of the quantitative data from the questionnaires, spouses were interviewed using an interview guide. Aiming for a variation in age, gender, and frequency of use or non-use of “narstaende.se,” 14 interviews with 12 participants were conducted, 10 during the illness period and 4 after the death of the patient. All interviews were conducted by the first author, with a mean duration of 35 min (range 8–59). Due to the Covid-19 pandemic, all interviews except one were conducted via telephone and audio recorded.

Analyses

Descriptive quantitative analyses of the questionnaires were done using the SPSS (Statistical Package for Social Science) version 27.0. Qualitative analysis of the interviews was initiated by transcript and repeated listening. All authors read the initial 4 interviews to get an overview of the content and acquired a sense of the whole. To further explore the content and experiences of “narstaende.se,” the interviews were analyzed through content analysis. Data were extracted using a deductive approach (Elo and Kyngas 2008), with questions from the questionnaires regarding the website used to build a categorization matrix. The first and the last author were mainly responsible for the process of extracting data, with the purpose of seeking and complementing information obtained in the questionnaires. The authors strived to stay close to the communication in the interviews focusing on the visible and obvious text. The extracted data was sorted into categories regarding (I) usability

Table 2. An overview of the informative texts presented in the domains on the website

<i>Support for you – being a family caregiver</i>
To ask for help
Being in need of and asking for help, whilst family and friends may feel insecure and perhaps withdraw and unexpected people step forward and offer help
Living with a seriously ill person
Reflections about putting one's own life aside, and about finding new activities together with the ill person that are possible to uphold
As death is closing in
Common signs and symptoms as death approaches as well as advice about what family caregivers can do
After death
Reflections on how life can be after the death of a close person and examples of what family members need to consider
Grief
Description of grief as a normal and expected reaction to different kinds of losses, recognizing each grief as unique and that people grieve in different ways
<i>How to give support</i>
Respiratory distress
Reasons for respiratory distress are described, as well as advice on how to support a person experiencing this kind of symptom
Loss of weight and appetite
Addressing the bodily changes causing decreased appetite and the changed situation around preparing and eating as well as psychological consequences
Constipation
Underlying causes to constipation and symptoms are described and advice is given about how to prevent and solve the problem if possible
Nausea
Description of different causes of nausea and how to support. Both practical and medical solutions are exemplified
Advice if you want to help with personal care including hygiene
Reflections on changing roles and advice if helping someone with personal care. Things that can be good to keep in mind from a purely practical perspective
Pain relief
A description of the various dimensions of pain. Medical treatment, side effects, and concerns about these are reflected on
Tiredness – fatigue
The particular tiredness called fatigue, a tiredness impossible to rest or sleep away, with its various expressions, is described
<i>Talk about it</i>
Children and young people as close relatives
Practical advice about how to talk to children and young adults and about things that may ease their everyday life when a close adult is seriously ill
Funeral/memorial ceremony
Conversations about funeral/memorial ceremonies, as being both challenging and contributing in the situation are reflected on

(Continued)

Table 2. (Continued.)

Death and dying
Addressing the challenges of talking about death and dying, especially when faced with the fact that both close persons and oneself are mortal
Family member – family caregiver
Reflections on the changing roles as family members often automatically become caregivers, although it can be more or less voluntarily
Society's support system, financial/legal aspects
Information about support systems in society, what kind of both practical and financial support to apply for, as well as information on juridical aspects

and acceptability of the website and the spouses' overall impression and (II) their use and experiences of the content and the different modalities. The process continued until no further data were left to extract. After this, the categories with extracted data were reviewed by all the authors to secure that they corresponded to each other.

Results

Participant characteristics

Altogether, 97 spouses were contacted by phone and 53 showed an interest in participating. Reasons for declining were having sufficient support ($n = 6$), being in a stressful situation ($n = 10$), the patient being too ill, close to death ($n = 10$), lacking access to a computer or tablet ($n = 4$), a negative attitude to internet solutions ($n = 1$), and unknown ($n = 13$). In total, 39 spouses of the 53 initially interested completed the baseline survey, after which they were given access to the website.

At follow-up, spouses were contacted before the questionnaire was sent and by then 4 spouses declined due to deteriorated condition of the patient, another 4 declined as the patient had recently died, and 2 spouses did not answer. The follow-up questionnaire was thus sent to a total of 29 spouses of whom 26 (90%) responded. Of the responders, 14 (54%) were women and 12 (46%) were men. The average age of the spouses was 63 years (range 27–80), 15 (58%) were employed, of whom 9 (35%) were partly off from work, financed by the social insurance system to care for the patient, and 11 (42%) retired. The average age of the patient was 65 years (range 27–79) (Table 3).

Overall impression

At second questionnaire follow-up, 18 (70%) of the 26 participants had used the website, 10 (56%) men and 8 (44%) women. Of them, 10 (55%) had used it once and 8 (45%) twice or more. All reported having used the website alone; however, in the interviews, one spouse mentioned that he had read texts and watched videos together with his ill wife. Among the users, 12 (67%) considered the website timely introduced and 17 (95%) would recommend the website to others in a similar situation (one missing answer) (Table 4).

In interviews, the website was described as warm, calm, and relaxing; this was illustrated by one spouse "The website was a place only for me, when I needed time to calm down and relax, to land, a piece in my grief puzzle, a small piece as I've been grieving for a long time, he's been ill for several years."

Table 3. Characteristics of participants

Characteristics	Participants (n = 26)
Age, mean (range)	63 (27–80)
Age of partner, mean (range)	65 (27–79)
Gender, n (%)	
Women	14 (54)
Men	12 (46)
Employment, n (%)	
Employed	15 (58)
Retired	11 (42)
Years as spouses, mean (range)	32 (3–52)
Relation to patient, n (%)	
Married partner	18 (70)
Unmarried partner	8 (30)
Education level, n (%)	
Elementary school	4 (15)
Secondary school	13 (50)
University degree	9 (35)
Diagnosis of patient, n (%)	
Cancer	24 (92)
Hematological malignancy	2 (8)
Years since diagnosed with the illness, mean (range)	4 (0–18)
Years since diagnosis of life-threatening illness, mean (range)	2 (0–6)

The website was perceived as easy to navigate and to get an overview of the content with videos and texts separated. “Instructive, good, well made.” Spouses perceived the content as giving a sense of acknowledgment, normalization, and recognition, providing comfort and understanding of oneself, which was valued. Described by one spouse in the questionnaire as “a feeling of being understood as a family caregiver, sharing thoughts, seeing the videos, reading the texts, is somehow healing reminding you that you’re not alone in the situation.” Further, strong feelings were evoked by using the website, as expressed by one spouse “Affected me a lot, but I realized I had to take control of my situation, and I’m very grateful I participated, I gained a lot of insights that were helpful.”

The digital format was experienced as convenient, “one can visit whenever one feels like it or has the time and energy.” Both among seldom users and nonusers, earlier negative experiences of social media contributed to some resistance to web solutions. There were also experiences of the digital era as “falling between the cracks” and some had log-in difficulties, needing help to reset their accounts, reflected by a spouse as “but I’m an old man.” Others who had not used the website or used it only to a lesser extent felt that they had sufficient support from families and friends, health-care professionals, or religious institutions. Spouses also described feeling tired due to caregiver strain or having problems concentrating, as reasons why they had not visited more often or had not read texts or seen videos to a greater extent. “It’s too much all the time.

Table 4. Use of the website and acceptability according to follow-up questionnaire

Have you used the website	n = 26 (%)
Yes	18 (69)
No	8 (31)
According to users of the website	n = 18 (%)
To what extent have you used the website	
More than 5 times	3 (17)
2–4 times	5 (28)
Once	10 (55)
Was the website timely introduced?	
Yes	12 (67)
No, it came too early	1 (5)
No, it came too late	2 (11)
Missing answers	3 (17)
Would you recommend the website to another person in a similar situation?	
Yes	17 (95)
No	0
Missing answers	1 (5)

I haven’t participated in the way I wanted, there’s so much to learn from it.” Spouses also expressed that they could need a reminder to use the website. They emphasized that it felt secure and good to know they could access the website at any time, saying “I know it’s there, for the moment I don’t feel bad. I want to focus on taking the day as it comes, just being with my wife.”

The timing of the introduction of the intervention was considered suitable by most spouses. There were also those who believed that the website would have contributed to a greater extent in their situation if it had been introduced earlier; this was the case especially if the patient had been ill for a longer period. In the interviews, it was obvious how the use of the website varied among spouses from accessing everything at once, briefly seeking information, perhaps watching the same video repeatedly, or simply orientated reading.

Videos, texts, link, and chat forum

Spouses considered the website contents, that is, videos, texts, links, and chat forum, relevant for them in their role as caregivers of a person with life-threatening illness. The possibility to access information via video, texts, or both was appealing as spouses described problems concentrating, some preferring reading, and others watching videos (Table 5). None of the content was regarded irrelevant although some spouses expressed “not needed at the moment.”

Videos

According to the questionnaires, 7 (39%) of the participating spouses had accessed videos on one occasion, 6 (33%) had accessed twice or more, and 5 (28%) reported not having accessed the videos. In the questionnaire, certain videos were reported as

Table 5. Use of the different modalities according to follow-up questionnaire

To what extent have you accessed videos?	<i>n</i> = 18 (%)
More than 5 times	2 (11)
2–4 times	4 (22)
Once	7 (39)
Not at all	5 (28)
Missing	0
To what extent have you accessed texts?	
More than 5 times	0
2–4 times	5 (28)
Once	8 (44)
Not at all	4 (22)
Missing	1 (5.5)
To what extent have you accessed links?	
More than 5 times	0
2–4 times	2 (11)
Once	3 (17)
Not at all	9 (50)
Missing	4 (22)
To what extent have you accessed the chat forum?	
Once	1 (5.5)
Not at all	16 (89)
Missing	1 (5.5)

especially meaningful, for example, “Being me,” “Meeting others,” and “Nice to have talked about.”

In the interviews, spouses expressed that the content was helpful, contributing to reflections about self-care and coping, guidance in questions regarding how to handle their everyday life and in important decisions as well as in aspects for the future, and inspired them to think through how time is spent. Descriptions of the videos were brought up, and the content had in some cases made deep impressions. The video “The loss” was considered as beneficial, prompting thoughts about how it will be after my partner has died. “I, myself, will actually be alone, sitting there,” helping in processing the situation. “When death is closing in” was described as a kind of comforting, to know how it can be. A sense of togetherness and sharing the situation was described, taking part of conversations via the videos, hearing others talking about their situation. The video “Withdrawal of treatment” was described as exactly what met one spouse’s needs; the video made a similar meeting at the hospital easier “then I thought of the video, my wife making her own decision, and then I said ok, I accept it, I supported her, that was good.” Another spouse mentioned videos encouraging spending more valuable time with his wife. On the whole, the videos were described by a female and male spouse, respectively, as “I really liked the videos, very nice, both the format and all the recognition” and “The videos being easy to access and suitably short.” However, in interviews, spouses also mentioned there were certain videos to which they did not relate. For example, the video “Concerns about the future” mentioned by one spouse as “it’s not the content in itself, it’s me. I’m used to managing everything by myself, I have no worries regarding practical issues.”

Informative texts

In all, 8 (44%) spouses had accessed the informative texts once, 5 (28%) twice or more times, and 4 spouses (22%) reported not having accessed them. In the interviews, texts about finances, writing a will, and funerals were highlighted as important. One spouse, after accessing information about funeral and finances, expressed “it opened my eyes to seeing death in a good way, preparing finances, funeral, talking through things with my wife and children.”

The need/wish to access information via texts varied among spouses; some found the shorter texts introducing each video sufficient, others preferred reading the longer texts.

Links

Links were used once by 3 spouses (17%), 2–4 times by 2 (11%), and 9 (50%) had not accessed links. In interviews, spouses described how they used links to get more specific information about things that were of importance to them and their situation.

Chat forum

The chat forum was used by one spouse. However, in interviews, spouses described that they had considered writing, saying they would appreciate to hear about others and their situation, also thinking they could be helpful to others. There was also hesitancy to use the chat forum due to earlier bad experiences. Concerns were raised that the chat could turn into being “all about me and my problems,” or cyber bullying, as they had these experiences from other social media.

Discussion

The findings of this study demonstrated that spouses of patients with life-threatening illnesses experienced the website, narstaende.se, easy to navigate and use, welcoming and calm, and with relevant and informative content. Spouses would recommend “narstaende.se” to others in a similar situation, and the majority found the website timely introduced. The online format was perceived to be flexible and convenient, but despite this flexibility, not all spouses visited the website, instead they expressed a wish for support IRL.

Spouses in the present study described the web-based format as timely, convenient, and flexible, delivered at the preference of their individual needs. Similar results were found by Duggleby et al. (2017), who described flexibility in terms of opportunities to choose which parts of the intervention to use and at what time. This is probably of utmost importance, as family caregivers, depending on their personal situation, have varying information and support needs (Poppe et al. 2020). Even though supportive IRL interventions often have positive effects (Ahn et al. 2020; Becque et al. 2019; Bilgin and Ozdemir 2022), it may be difficult for family caregivers to attend. Earlier studies have shown that predominantly less vulnerable, highly motivated family caregivers are those who most often participate (Holm et al. 2015b, 2017). Web-based interventions, such as narstaende.se, could be regarded as a possible alternative to reach more burdened or vulnerable family caregivers (Kaltenbaugh et al. 2015; Kleine et al. 2019), as well as family caregivers living in rural areas (Song et al. 2015). Family caregivers who experience more strain, complex caregiving demands, emotional isolation, and with fewer resources have been shown to be more engaged in web-based support (Friedman et al. 2018;

Washington et al. 2020). Despite the benefits of web-based support, recruiting participants can be difficult (DuBenske et al. 2010; Northouse et al. 2014; Ruland et al. 2013), as was the case in this study. However, participants, once recruited, also seem to retain to a higher degree than in IRL interventions, thanks to the possibility to complete the program from home (Northouse et al. 2014). Further research is needed to study web-based versus IRL interventions for family caregivers, but the limited existing literature supports the adaption of caregiver interventions to web-based formats (Kaltenbaugh et al. 2015).

In the present study, spouses appreciated the videos most among the modalities in the web-based intervention, providing a recognition factor. Also Leow et al. (2015) and Leow and Chan (2016) found that the video format was appreciated by family caregivers and suggested videos as a future intervention delivery tool. Videos as a tool have also recently been regarded as promising in hospice and palliative care for family and patient education according to a systematic review by Cruz-Oliver et al. (2020). In the present study, spouses described that they felt like they were actually sharing the conversations on the videos, providing them with comfort and a feeling of not being alone. This could be compared to the beneficial experiences of attending a program IRL demonstrated in previous studies (Henriksson and Arestedt 2013; Hudson et al. 2013; Milberg et al. 2005). Henriksson and Andershed (2007), for example, found that family caregivers especially valued listening and accessing the experiences of others, as they found it comforting and gave a sense of belonging. Even though sharing with others in similar situations seems to be of importance, only one spouse in the present study posted on the chat forum. However, several of the spouses talked about the chat forum as something they had considered participating in. This kind of hesitant attitude regarding chat forums was reported by Leow et al. (2015). In their intervention, 25% visited, but no one posted on the chat forum as they reported feeling uncomfortable sharing things with strangers. In the present study, earlier bad experiences from social media were described by spouses, with an ensuing ambivalence toward web-based solutions. Studies regarding online support groups (Benson et al. 2020; Washington et al. 2020) state the value of a professional facilitator, and perhaps this could be a way to encourage communication on the chat forum, since spouses regarded it of interest. Online networks driven by both health-care providers and patients or caregivers have lately been increasingly used (Finucane et al. 2021).

Spouses in the present study emphasized the intervention content that was related to death, dying, and the time following death. This is comparable with the results in a study by Washington et al. (2020) exploring factors influencing engagement in online support groups for family caregivers, which found information about the dying process and pain especially engaging. Perhaps this can be explained by the fact that we have a culture of death denial in our modern society, with death medicalized, seen as a failure in the treatment of medical conditions, instead as a natural part of life. A recent report from the Lancet Commission (Sallnow et al. 2022) highlights the importance of bringing death back into life and states language, knowledge, confidence to support, and manage dying being lost.

Methodological considerations

Strengths of this study include the data collection combining different methods, which provide both quantitative and qualitative perspectives, leading to a richer understanding of spouses' experiences

of the website. However, there are also limitations to consider. First, recruitment was from a metropolitan region; perhaps, the results had been different among spouses in rural areas. Also, the sample is limited, recruitment being more difficult than expected, based on experiences from IRL interventions, partly explained by the Covid-19 pandemic. Despite several tests of the log-in procedure, some spouses had problems with it after answering the baseline survey, which might have affected their possibility to take part of the website content. Technical limitations barred the authors from accessing usability data in terms of frequencies of visiting different modules, thus relied solely on self-reports. Further, spouses mentioned that a reminder to visit would be useful. Access without any set time frame may have influenced spouses' inclination to visit the website compared to scheduled intervention meetings.

Presumptions might exist that web-based solutions are less accessible to the older population. However, according to the yearly investigation made by the Swedish Internet Foundation, the use of internet in Sweden is constantly rising. In 2021, 94% of the adult population uses internet, and of them, 90% daily. Among those over 65, the internet use has become more common, with 80% using internet the last years (Internetstiftelsen 2022). In a study as small as the present one, it is difficult to make any conclusions regarding differences in accessibility according to age; however, in a study with a larger sample, this could be further explored.

Conclusion and future research

Web-based interventions such as "narstaende.se" seem acceptable and useful for spouses of patients who are cared for in specialized home care; however, the web-based format may not be suitable for everyone. To be able to choose content and modality according to your own needs, energy and the phase of the illness were beneficial. Videos seemed most easily accessible and were most used, contributing to a feeling of sharing the situation. For future research, a moderated chat forum combined with the website could be considered. Further, a randomized design with a larger sample, evaluating outcomes such as preparedness for caregiving and death, support needs, quality of life and health, could provide results of higher standard. In such a study, caregivers other than spouses could also be included as the website content might be relevant to parents, siblings, children, or others.

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