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The art of living with cancer at an advanced age

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CHAPTER 7

General discussion and conclusion

INTRODUCTION

Spring 2021: for about a year, the world has been gripped by the COVID-19 pandemic. In the Netherlands and many other European countries, the first ‘corona wave’ was followed by a second wave and additional measures (i.e. lockdowns). In some countries, the number of infections and hospital admissions is going through the roof, and many people are anxiously awaiting large-scale vaccination.

Needless to say, this thesis is not about COVID-19 or the experiences of older people with COVID-19, but there is a similar inverse relationship between the number of older people being affected by either COVID-19 or cancer and the attention paid to the lives of these people. During this pandemic, older people appear to have simply disappeared. Locked away in nursing homes or too afraid to leave their houses due to a highly contagious disease lurking anywhere around them. Although protecting the lives of (older) people is a top governmental priority, the experiences and quality of life of older men and women themselves receive little attention. In contrast, concerns about the well-being of younger people are daily news. As with cancer, the psychosocial consequences for older people, therefore, remain underexposed.

In these times of global health crisis, it is slightly more difficult to concentrate on cancer. At the same time, keeping people with cancer and other chronic diseases in the picture is all the more important because COVID-19 is not their only concern: for many chronically ill persons, COVID-19 comes on top of other problems and can exacerbate these problems, such as when cancer treatments have to be delayed.

After a discussion of the experiences of older adults with cancer in the quality of life domains, some attention will therefore be paid to the current – urgent and complex – situation in which COVID-19 may severely affect the lives of older adults with cancer. This discussion chapter will conclude with practical implications and some issues that require further research. It will reflect on what needs to be done to bring the care of older adults with cancer to a higher level.

Attention for older persons with cancer

Even though the scientific attention for older persons with cancer appears to increase, neglecting older persons, during and beyond this pandemic, is worrisome. It is high time that the low awareness of issues related to older adults with cancer among the general public, as well as among policymakers, is addressed. Patients' narratives, gathered in a scientific manner, can be helpful in this respect, since the story of a patient can be both comprehensible and convincing (Mohile et al., 2016). To a great extent, this thesis is based on the narratives of older adults with cancer, which reflect

their experiences with having cancer and the care they receive from health care providers and people in their environment.

The main results of our studies will be briefly summarised and discussed along the quality of life domains, which represent physical, psychological/emotional, social, and environmental aspects. We added spirituality to these domains because religion and faith appeared to provide guidance for a substantial number of older adults with cancer. Nevertheless, providing a complete overview of the experiences of older adults with cancer is easier said than done, since these experiences cover so many different aspects and show considerable variety. Moreover, quality of life itself is not well-defined and, therefore, difficult to measure (NWO, s.d.). A Task Force of the International Society of Geriatric Oncology stresses the importance of addressing the quality of life needs of older people with cancer, and also acknowledges the perspective of the patient and the patient's personal interpretation of quality of life (Scotté et al., 2018). We did not inquire about the quality of life of our respondents directly, but are nevertheless convinced that the experiences and narratives of older adults with cancer reveal much about their well-being and quality of life. Within each domain, one or several aspects will be highlighted.

The physical experiences of older adults with cancer

With regard to the quality of life domain of physical functioning, the variety between older adults with cancer is impressive. As described in Chapter 3 and 4, some men and women reported very few or even no limitations and side effects caused by cancer and its treatment, while others were severely restricted due to fatigue, surgical wounds, pain, incontinence, impotence and so on. Noteworthy is the influence of comorbid diseases on physical functioning, as several women with breast cancer indicated that they were more limited by other diseases than by cancer itself. In our discussion paper about gender differences (Chapter 6), we described that multimorbidity appeared to limit women to a greater extent than men, while men were more affected by cancer alone or by one or two significant illnesses. Nevertheless, multimorbidity is extremely common at an older age, with cardiovascular diseases, arthritis, diabetes, depression, and COPD among the ten most common chronic conditions in addition to cancer (Williams et al., 2016). In general, more than 90 percent of older persons with cancer have at least one comorbid condition, and comorbidity negatively affects functioning and increases the risk of death (Williams et al., 2018). Treatment decision making is more complicated in persons with other chronic diseases besides cancer, and both recovery and quality of life are hampered (Cavers et al., 2019). Among older survivors with cancer, having three or more comorbid illnesses is a strong indicator of poor health, even more so than having survived cancer (Sulicka et al., 2018). Although not synonymous with multimorbidity, frailty is also a general indicator for the

risks of treatment side effects and increased mortality and is common among older patients with cancer (Handforth et al., 2015). The complex combination of cancer, comorbidities, and frailty requires more research on the topic (Cavers et al., 2019).

Regardless of the presence or absence of other chronic conditions, older patients with cancer report that the absence of pain and being mobile and in good health are important determinants for high quality of life (Matelot et al., 2020). Although we focused on breast, prostate, and colorectal cancer in particular, the narratives of older cancer survivors with various stages of bladder cancer, colorectal cancer, Non-Hodgkin Lymphoma, and lung cancer confirmed the differences in symptom severity (Kornblith, 2020). Interestingly, symptoms and limitations such as pain, fatigue, changes in body image, sexual problems, and problems with the intake and enjoyment of food were predominantly attributed to treatment side effects rather than to cancer itself (Thomé et al., 2003).

In short, cancer, cancer treatment, ageing, and comorbid diseases – especially in combination – can severely hamper the quality of life of older persons. A cancer diagnosis is not necessarily a conviction to physical misery, but many older people experience limitations in physical functioning to a greater or lesser extent.

Coping with cancer

Psychologically, many of the older persons in our studies coped well with having cancer. As described in Chapter 6, gender differences exist but individual differences probably outweigh the differences between men and women. For some men and women, getting cancer was a big shock, while others accepted their diagnosis and tried to get on with their lives as well as possible. Staying active was important to many patients during and after treatment, but when physical limitations hampered daily life and social contacts, this could pose a threat to mental health as well. Moreover, our study on the experiences of older patients with colorectal cancer (Chapter 5) showed that respondents with lower perceived health levels were less satisfied with the hospital care. Poor health can affect several other areas of functioning. Besides trying to stay active, some other coping mechanisms used by the older women with breast cancer and older men with prostate cancer were information seeking, humour, and having an optimistic and strong attitude – ‘I take care of myself’. Seeking support is also an important way to deal with physical and mental challenges; as described in the next paragraph.

Although most participants in our studies did not appear to be cognitively impaired or overtly depressed, a single patient did report feeling depressed and having difficulty expressing himself for no apparent cause. Lack of insight into his physical

and mental problems made him feel insecure. Other effects of cancer that could evoke feelings of insecurity, sadness, or anger were changes in appearance in women and reduced feelings of masculinity in men. Neglect of these consequences by health care providers made them more difficult to deal with.

The stories of older adults with cancer as described in 'Older Survivors of Cancer' (Kornblith, 2020) were largely comparable with our participants' experiences and also showed some coping mechanisms not yet discussed. It is noteworthy that many older survivors in Kornblith's book spoke about their 'fighting spirit' and the advantage of having overcome other problems during their lives. They also coped by accepting their situation, trying to stay active, and keeping a positive attitude. Gratitude was strikingly common among the older survivors. They were grateful for the life they had led, for the support they received from family members and friends and especially for the care they received from the hospital. Still, for some, fear of cancer recurrence and feeling alone and misunderstood made living with cancer more difficult. A comparison study showed that, compared with younger adults, older persons with cancer were better able to reconcile themselves with having cancer (Hernández et al., 2019).

Although only few of our participants mentioned the use of humour, it can make a valuable contribution to coping with cancer. It is important to realise that even in difficult and precarious situations, such as during palliative care, humour has many advantages. If used sensitively, humour can relieve suffering, reduce pain, tension, and stress, amplify feelings of warmth and the idea of being seen, increase proximity between patient and carer, and contribute to maintaining dignity (Bogers et al., 2018). Moreover, humour can help patients handle challenging situations and express their feelings or criticism towards health care professionals (Åstedt-Kurki et al., 2001). Research has shown that older people who tend to use humour cope more efficiently with life stressors and report greater satisfaction with life (Wanzer et al., 2009). However, some people – especially men – may use humour as a way to avoid difficult situations (Åstedt-Kurki et al., 2001). The use of humour is, therefore, individual and age-dependent, since older adults appreciate different types of humour than younger adults (Wanzer et al., 2009).

The psychological domain shows a wide array of mechanisms that help older adults cope with cancer. These mechanisms may be beneficial to their quality of life or be more likely to restrain their well-being in case of denial, rumination, and avoidance.

Cancer in the social domain

The studies on breast and prostate cancer (Chapters 3 and 4) and the discussion paper on gender differences (Chapter 6) demonstrated that some of the most notable differences between older men and women concern social relationships. Briefly, older women have a greater social network to draw on, and they talk more about emotional issues than older men, who tend to rely on their partner to a greater extent and are more reluctant to discuss cancer and cancer-related topics with others.

Older patients with cancer report that a good relationship with family and friends and the absence of worries about relatives are among the most important determinants of a good quality of life (Matelot et al., 2020). Interestingly, these older patients also reported that being mobile without the help of others is an important factor related to a high quality of life as well. This appears to correspond to our finding that some older persons – especially men – preferred to travel to the hospital and medical appointments alone, and emphasised their independence.

Persons whose spouse has recently passed away may find themselves in a difficult situation. They have to cope with feelings of grief in addition to handling cancer and lack an important potential source of support. For older adults without a partner, those in an unsupportive relationship, and those taking care of a severely ill spouse themselves, the supportive scale may become unbalanced. Moreover, unmarried participants, as well as participants with high levels of physical impairment and persons of non-white descent, were most likely to have unmet social support needs according to a study on older adults with cancer. And the greater the number of unmet social support needs, the lower the level of health related quality of life (Williams et al., 2019). Interestingly, having a pet can be very important to well-being. Although we did not notice this source of support in our studies, many older cancer survivors have reported the importance of their pet as a companion (Kornblith, 2020). It is highly conceivable that a pet can bring comfort and consolation, although the care-taking responsibilities should also be taken into account in case of hospitalisation and severe mobility problems of the pet owner.

Although the role of professional support will be elaborated on later, one particular aspect will be highlighted here briefly. Whilst most older adults in our studies were very satisfied with the support they received from the hospital, older adults with colorectal cancer reported lower satisfaction with the hospital when they received professional support at home after discharge (Chapter 5). This partly corresponds with older people with cancer reporting lower quality of life when they receive support in daily living (Thomé & Hallberg, 2004). It is highly plausible that those people most limited in daily life will be more likely to receive support at home.

Treatment without a desired outcome (i.e. getting better) may lead to a necessity for support at home and lower satisfaction with hospital care at the same time. Although more research on this relationship is necessary, support at home is, in any case, an important aspect for patients with (colorectal) cancer (Bailey et al., 2004), which underscores the importance of proper aftercare. That aftercare can enhance patient satisfaction is reflected in the unanimous appreciation among the older women with breast cancer of the availability of nurses until years after treatment has ended. Professional support needs to exceed hospital boundaries effortlessly. Multidisciplinary consultation and collaboration are therefore crucial.

Cancer and the environment

Although the environmental domain appears to be less well studied than other quality of life domains regarding cancer, people living in socio-economically deprived or remote areas have a higher risk of dying from cancer compared with people in less deprived and urban areas (Tervonen et al., 2017). Moreover, the environment one lives in influences experiences around having cancer and quality of life. An older person who is a non-native speaker and lives in a small urban run-down apartment with children and grandchildren probably has different experiences and needs than an older married person living in the countryside. Our study population mainly existed of older adults who lived independently in a single-family home or apartment, with or without a partner. The most striking environmental issue in our studies was transportation to the hospital. Several older men with prostate cancer insisted on visiting the hospital independently, while women without their own transport often relied on family members and friends or used municipal taxi transport. In general, they managed to attend their medical appointments without much trouble. In other countries, however, difficulties in reaching oncologic care negatively affected cancer diagnosis, cancer treatment and outcome, and quality of life (Ambroggi et al., 2015). Another study demonstrated that mobility-related issues such as the steepness of the driveway, the ability to use the bus, and the presence of a garden were related to feelings of independence and quality of life, and eventually could influence the decision whether or not to continue living at home. Nevertheless, many older persons with terminal cancer living alone at home wanted to stay there as long as possible, even though their illness and resultant limitations restricted their freedom and autonomy (Aoun et al., 2016).

Besides transport and mobility, more research on the association between environmental factors and experiences with cancer in older adults is needed. Conversely, there is a reasonable amount of research on the environment as a risk factor for developing cancer. These environmental risk factors include, among others, smoking, alcohol consumption, being overweight, inadequate sanitation, chemical

exposure, and a family history of cancer (Queiroz et al., 2018; Spinelli et al., 2010; Woodman et al., 2020). However, while this demonstrates the intricate relationship between cancer and the environment, the focus of this thesis is not on risk factors but on the consequences of having cancer.

Last but not least, in our systematic review (Chapter 2), we stated that patient navigation interventions concern transportation issues and accessibility of oncologic care. Because none of these interventions focused on older adults in particular, the opportunities for patient navigation to assist older adults to and through the hospital environment are as yet unexplored. Nevertheless, the practical navigation approach may be a valuable addition to other psychosocial approaches, especially with regard to the environmental domain.

Spirituality

Like so many other concepts, spirituality – and derivative terms such as spiritual development and spiritual health – have many different definitions. However, several authors agree that although spirituality is broader than religion, spirituality often includes religious elements or the belief in a higher being (Jewell, 2004). Other elements of spirituality include meaningfulness, purposefulness, transcendence, hopefulness, harmonious connection with others, and holistic integration, which refers to the intertwining of physical, mental, social, emotional, and spiritual needs relating to the inner being of every person (Jaberi et al., 2019; Jewell, 2004). In a sense, a holistic approach aims to amalgamate the quality of life domains described in this discussion section.

Within our study population, spirituality was partly related to faith. Some older men and women turned to God during difficult times or felt supported by his presence. However, being able to offer support to other people – rather than mainly receiving support – significantly contributed to feelings of belonging and meaningfulness. Taking care of grandchildren, for example, could result in receiving a drawing or the touching question ‘Grandpa, do you still have cancer?’. Some participants developed the ability to enjoy the ‘small’ things in life, such as the woman who cut all the positive news items out of the newspaper. As a result of having breast cancer, she acquired a much more optimistic outlook on life. Several respondents also described accepting the situation as it was as a spiritual element.

These results are in line with the narratives of other older persons with cancer (Kornblith, 2020). As described in the paragraph on coping, many older adults reported being grateful. Acceptance and gratefulness can be considered spiritual coping mechanisms, which require a less active attitude and the ability to let go of

pursued desires (e.g. the desire to be fit and healthy), and being grateful for what is present. For some persons, satisfaction with their life as lived and being aware of the coming completion of life made living with cancer more bearable (Thomé et al., 2003). Interestingly, some older adults described having become a nicer and more empathic person (Kornblith, 2020). Nevertheless, for others, having cancer could result in feeling misunderstood, abandoned, or angry.

Several studies report a positive association between spirituality or spiritual health and quality of life and well-being (Bai et al., 2018; Jaber et al., 2019; Pahlevan Sharif et al., 2020; Zavala et al., 2009). However, a review of the literature showed that the direction of the relationship is unclear and in many questionnaires, spirituality and well-being items show content overlap (Visser et al., 2010). According to the authors, more longitudinal research is therefore needed.

As described above, cancer can adversely affect quality of life in older persons in different domains, but the relationship is not always negative or straightforward. Severe physical limitations may result in deterioration of social relationships but may also generate unexpected sources of support. Coping mechanisms can promote or hinder physical recovery, and spirituality may reduce anxiety and help with coming to terms with oneself and one's illness. According to life span developmental models, the ability to deal with chronic illness in old age should be seen as the outcome of lifelong development and innate and acquired resources such as intelligence, mastery, and support. The trajectories from early losses to adequate or poor adaption to chronic illness later on range from vulnerability to resilience trajectories (Aldwin, 2009). These models show that coping with cancer is not a static fact but the outcome of a dynamic process. This may also explain the wide variety of individual experiences of older adults with cancer. Regarding our objective, it is important to value individual differences and use these experiences to offer guidance to health professionals who take care of older persons. But before we turn to the practical implications of our research, first a reflection on the current situation with COVID-19 and its impact on older adults with cancer, since this pandemic is likely to complicate living with cancer and the ability to offer support.

CANCER AND COVID-19

Unfortunately, older (as well as younger) persons with cancer are particularly affected by the, as yet, elusive disease officially known as coronavirus SARS-CoV-2. Instead of the double trouble of having cancer and dealing with the consequences of ageing, older persons with cancer are hit threefold these days: they have a life-threatening illness; decreasing mental, social, and physical capabilities (including comorbid

diseases); and they are hit the hardest by an infectious disease that not only threatens their life directly, but also endangers their cancer treatment.

Numerous experts warn about the detrimental effects of COVID-19 in older persons and those with non-communicable diseases such as cancer, cardiovascular diseases, diabetes, and Parkinson disease. For example, more than 32 percent of patients with cancer and COVID-19 in Cuba have died, compared with 3.5 percent of COVID-19 patients without cancer (Rubio et al., 2020). A study conducted in the USA, Canada, and Spain showed that mortality in patients with cancer and COVID-19 was 13 percent within thirty days after infection alone. In addition to other factors, mortality was higher among older and male patients and among patients with comorbid diseases (Kuderer et al., 2020). In general, persons with non-communicable diseases and multimorbidity are at increased risk of premature mortality once infected with this coronavirus (Azarpazhooh et al., 2020).

Many uncertainties exist regarding the specific impact of COVID-19 on patients with cancer (Serraino, 2020), but it is clear that this impact goes far beyond actual infection. Due to COVID-19, the number of cancer diagnoses has dropped – and will surface at a later stage – and cancer treatments have been postponed (Sharpless, 2020). Moreover, many clinical trials have been delayed, new drugs will not be available for months, and cancer research is coming under pressure due to loss of funding at universities (Harris, 2020). Not to mention the fear of infection on top of having cancer, social isolation in periods of lockdown, and overburdened health care workers who may not be able to offer the care they used to offer. These are complicated times to live in for most people, but we must not forget that this is probably even more true for older persons with cancer. If there is one thing this pandemic has made clear, it is the deeply human need for contact with fellow humans and the feelings of loneliness and desolation that may result from social isolation. In addition to acute medical care, both cancer and COVID-19 require a humane approach, and older people should not be forgotten. A study on the experiences of older survivors of cancer during the COVID-19 pandemic showed that these older participants could very well generate ideas for care adjustments and improvements. For instance, they wanted more information about the changed situation caused by COVID-19 and valued the use of technological equipment, although they preferred face-to-face contact (Haase et al., 2020). Nevertheless, more research is needed into the consequences of COVID-19 for older people with cancer.

CLINICAL IMPLICATIONS

Human-centred care for older persons with cancer

Psychosocial oncology has been an established discipline for decades now and makes an important contribution to non-medical care for people with cancer. Attention to psychosocial needs, including family members, personalised information, and care coordination are important elements of psychosocial health care (Institute of Medicine, 2008). Person-centredness should be central to treatment but, like similar concepts, carries the risk of remaining an empty term without a concrete description and guidelines. Few people will object to personal, individual, tailored, or patient-centred care, but what exactly makes care personal or patient-centred? Fortunately, some authors have tried to conceptualise person-centred care and combined several definitions into one overarching description:

‘Person-centred care is a holistic (bio-psychosocial-spiritual) approach to delivering care that is respectful and individualized, allowing negotiation of care, and offering choice through a therapeutic relationship where persons are empowered to be involved in health decisions at whatever level is desired by that individual who is receiving the care.’ (Morgan & Yoder, 2012, p. 3).

According to the authors, holistic, individualised, respectful, and empowering are key elements of person-centred care. Their conceptualisation, however, barely transcends the abstract level. Moreover, although there is little to criticise in person-centred care principles, some important premises of care, such as a caring attitude and compassion, are lacking. In addition to high-quality medical care, the basis of care should first of all be human-centred.

Human-centred care carries much of the elements of person-centred care, but is based on the belief that care should be humane. This may seem obvious, but our participants' stories have taught us that a humane approach is not always present during clinical encounters. A striking example of insensitive care is described in Chapter 4, where one of the participants with prostate cancer was rudely told to have his coffin ready in a year and a half. Comments like these do not contribute to an effective relationship between care seeker and care provider. A more sensitive approach from alert care professionals who meet their patients as fellow human beings and focus on the well-being of the individual is required (McCluskey, 2005). Alternatively, in other words: ‘Care requires professional competence and training, but also individuality, emotion, solidarity, sensitivity, and ethics. It requires excellent social and communication skills, empathy, active listening, respect, and compassion to others’ (Nin Vaeza et al., 2020, p. 385).

More than forty years ago, in his much-discussed book 'Limits to Medicine', Ivan Illich argued that the industrial approach to disease and health has robbed people of the art of suffering (Illich, 1977). Perhaps, it has robbed the medical and nursing professions of the art of care-taking as well. Although the limitations of medical care have been stretched greatly over the last forty years, humane care is easily compromised when the pressure on care is high and care must be provided with insufficient numbers of care professionals. The fact that in recent times more and more professionals seem to recognise the importance of humane care offers hope. Perhaps a crisis is needed to clarify the necessity, as Diederik Gommers, endowed professor of intensive care medicine, reported in a national newspaper: 'If we have learned anything from COVID-19, it is the importance of humaneness' (Weeda, 2020, p. 44). In this interview, he argues for less administration and better ICT systems so that nurses have more time to provide loving care. Of a similar nature are the stories described by lung specialist Sander de Hosson who makes a plea for humane healthcare (De Hosson, 2018). Moreover, several medical specialists have indicated how their experiences as a patient have changed their view of healthcare and the communication with their patients, resulting in a more empathetic approach (Diemel, 2019). As mentioned before, narratives can improve insight into patients' experiences and offer concrete directions for care improvements. They provide insight, evoke empathy, and contribute to patient-provider communication in which listening and exchanging and comprehending information contribute to healing (Marini, 2019). The experiences of older adults with cancer in our studies have shown that some factors particularly contribute to human-centred care.

First of all, one of the most striking findings from our studies was the strong association between the reception at the hospital and overall satisfaction (Chapter 5). This means that the focus should not just be on doctor-patient or nurse-patient interaction and communication but should be broadened to include other staff members as well. A friendly smile upon entering the hospital, attention to individual needs and potential insecurities, a friendly explanation, patience, and offering a cup of coffee or tea in the waiting room may help to put patients and family members or friends at ease. Older people, in particular, may need a little more help and time to navigate the hospital environment. To be met as a person starts upon entry, not in the doctor's office. As described in 'If Disney Ran Your Hospital', health care organisations can learn from the hospitality industry when it comes to a respectful treatment of and attitude towards patients (Lee, 2004).

Secondly, human-centred care means that care professionals themselves are available and responsive to individual needs. This includes being available to listen to the patient's story, answer questions, and provide information in a way that is

manageable for the patient at a certain moment. A good example of receptivity in a study on human-centred design in cancer care is the anxiety-reducing measures taken at a radiation department, after quick ethnographic research had shown that some fixation techniques provoked panic attacks in some patients. Cutting holes in a fixation mask, for example, immediately reduced levels of anxiety (Mullaney et al., 2012). Moreover, moving projections of nature increased the amenity of the room, which also reduced anxiety during radiotherapy (Zijlstra et al., 2017). Change does not have to be dramatic; small adjustments can have a significant effect on the patient's experiences.

Thirdly, the elements that are part of person-centred care also apply to human-centred care. Holistic treatment, in particular, is important for older persons. Due to comorbid illnesses and decreasing physical and mental reserves, their health status can be complicated. Geriatric assessment and multidisciplinary consultation may therefore be necessary and may include the use of supportive care measures throughout the disease process, from the moment of diagnosis to palliative and terminal care (Steer, 2016). It is important to inquire about social and supportive relationships, financial situation, living environment, and spiritual aspects, but more sensitive topics such as sexuality and approaching end of life should not be forgotten. The question 'What is important to you?' must be asked and answered before deciding on a type of treatment. Some older persons are willing to take treatment side effects for granted, while others prefer to spend their last months of life with their loved ones without excessive medical fuss. Figuring out what is important to older adults takes time, but can ensure that a person is more motivated to start and complete treatment or to accept its limitations. The holistic approach is individualised, respectful, and empowering at the same time if personal wishes are taken into account. This may be more difficult when family members appear to influence the choice of treatment or if an older adult prefers to 'let the doctor decide'. It must be kept in mind that around half of older adults does not want to be more involved in making decisions or executing health behaviours (Rietkerk et al., 2020). As a minimum, the reasons for and consequences of this limited self-direction should be discussed and understood.

In addition, human-centred care takes into account the capabilities and limitations of older care seekers. Many older adults are quite able to communicate with doctors, manage their own care, search for information on the Internet, and mobilise support. However, more than a third of persons aged 65 years and older in the Netherlands have limited health literacy (Heijmans, 2019), which may result in poor communication with care providers, increased hospitalisation and healthcare utilisation, lower treatment compliance, and ultimately worse health outcomes and premature death

(Heijmans, 2019; Koay et al., 2012). Care providers should be alert to people who try to conceal their limited health literacy, and adapt their communication to the capabilities of the care recipient (Heijmans, 2020).

In the fifth place, a human-centred approach means that doctors and nurses are human too, and therefore fallible (Nin Vaeza et al., 2020). The two complaints that older men with prostate cancer had filed against the hospital (Chapter 4) were partly due to premature discharge from the hospital. What troubled one man most, however, was the handling of his complaint by the hospital. He did not feel heard. Another man had received insufficient information about his catheter use and therefore had to return to the emergency department in the middle of the night. These are just some examples of what can go wrong during and after treatment. Mistakes can be made, operations may fail, and treatment may not have the desired effect, but openness about procedures and admitting mistakes can prevent worse outcomes. Poor communication, on the other hand, can produce very negative treatment experiences and ruin the patient-provider relationship.

Finally, as described in the paragraph about coping, humour has many advantages and fits well within a human-centred approach. It can be used deliberately to make communication run more smoothly and is a vital element of communication between patients and healthcare providers (Samant et al., 2020). Healthcare providers should be aware of positive and negative types of humour and the effects on older adults and should not make humorous remarks if they feel uncomfortable doing so. In Chapter 6, we have provided some examples of the use of humour with men; whether women value humour to the same extent needs to be investigated further.

To clarify the above, here is a perfect example of a human-centred care. Some of the older men with prostate cancer we have interviewed were surprisingly satisfied with radiotherapy treatment. They could schedule the frequent appointments at times that were convenient for them. If they came by car, they received a parking ticket to park close to the hospital. In the waiting room, they often had interesting conversations with fellow patients, and during radiotherapy sessions, they joked with the radiotherapy staff. As described in Chapter 4, these appointments were like an outing to some of them. With this human-centred approach, the entire department contributed to turning an uncomfortable treatment into an almost enjoyable treatment experience.

Human-centred healthcare providers

Older adults with cancer often have to deal with a considerable number of healthcare providers. The more complex their health situation, the more healthcare providers

they will meet. The question is whether all care providers are sufficiently suited to provide human-centred care. Ideally, all professionals have a human-centred attitude and skills. Nurses, oncologists, geriatricians, and primary care providers working with older people should all respect their complexity and individuality. Unfortunately, there are several extreme, as well as more subtle, examples of care professionals who still lack the skills to relate to their patients in an attentive and sensitive manner; they lack kindness (Marini, 2019).

One of the reasons for poor communication is the influence of ageism and prejudice against older adults, which negatively affect cancer treatment and care and must therefore be counteracted (Bagayogo et al., 2020). To do the experiences of older people with cancer justice and offer them the care they need, first and foremost we have to change the negative stereotypes. People may adhere to a so-called Ideal versus Real Cultural Model in which the 'Ideal' part represents the positive aspects of ageing which are emphasised or idealised (such as activity, self-sufficiency, and increased wisdom). Nevertheless, they easily slip into the predominant 'Real' aspect of the model, in which ageing is characterised by a negative viewpoint (i.e. deterioration, fixation and even loss of capabilities and control, inability to keep up with technological changes) (Lindland et al., 2016). The lack of positive media coverage and the setting aside of older people as dry wood – as happened recently during the COVID-19 crisis – fall into the latter category and do not in the least promote human-centred care for this age group. Language is very important in this respect, since statements such as 'A tsunami of the elderly' and describing the process of getting older and having cancer as 'A struggle or battle' (Fick & Lundebjerg, 2017) will not increase a respectful treatment of older adults, nor will it motivate young professionals and students to work with this diverse and interesting group of people. It is worrisome that the attitude of nurses and nursing students towards older people seem to have become somewhat less positive since the beginning of this century (Liu et al., 2013). Nurses may be the most involved with older persons with cancer and have the broadest insight into their lives and well-being (Bagayogo et al., 2020). They must therefore be properly equipped to offer human-centred care. Research has demonstrated that good nurses know how to tune in to the norms, values, and preferences of individual patients and their families. This knowledge ('afstemmingskennis' in Dutch) enables nurses to connect with the experiences of their patients and offer the best possible care which contributes to a better quality of life (Den Hertog-Voortman, 2015). However, because treating this population is obviously not the sole task of nurses, other care providers must be trained to offer human-centred care as well. This creates an important task for medical and nursing studies: to educate students about the high numbers of older persons with cancer, to identify and discuss stereotypical ideas, and to motivate young people to work with

this interesting group in a human-centred way. Moreover, improved care for older persons with cancer is impossible without teaching oncologists and other health care providers the principles of geriatric oncology (Hsu et al., 2020).

LIMITATIONS

Due to the mixed-methods study approach, this thesis provides a broad and in-depth picture of the experiences of older people with cancer. Nevertheless, there are a number of limitations. First of all, the cross-sectional and partly qualitative nature of our research provided information about the experiences of older people at a particular point in time but prevented us from making any statements about causality (Carvalho et al., 2018). Longitudinal research can provide information about processes and mechanisms and contributes to better insight into the development of older adults' lives from cancer diagnosis to post-treatment.

Secondly, although we aimed to recruit a wide variety of participants aged 70 years and older, this diversity has not been equally successful in all areas. The age range of older men with prostate cancer was quite small, from seventy to eighty years of age, while the variation in ethnic origin, in particular, was limited. The majority of men and women in our qualitative studies were white Dutch participants. In the survey that was sent to older men and women with colorectal cancer, we inquired about nationality. We realised only afterwards that asking about their country of origin would have been more informative. Nevertheless, we assume that nearly all older persons with colorectal cancer were born and raised in the Netherlands as well, with the exception of a single German participant. The bottom line is that we know a significant amount about the experiences of this group of older adults with cancer, but much less about other ethnic groups. With the ageing of society, there will be more Moroccan, Turkish, Surinam, and older people with different origins who may have different experiences with cancer than the men and women in our studies.

A third limitation is that we have not interviewed partners or other persons who are close to the older adults. There is an extensive body of literature concerning the needs of caretakers of people with cancer, but older partners may find themselves in a complicated situation when they are ill or frail themselves. Of course, this also applies the other way around, since several respondents indicated that their spouse had fallen ill or had recently passed away. For others, the relationship with a partner (or children) did not always appear to be harmonious. Interviews with partners would have provided a more complete look at the lives of older people and the dynamics of close relationships in times of cancer.

Fourth, because we have focused on the wide range of older people's experiences with cancer, some aspects often associated with cancer, as well as individual cancer types, have not been thoroughly elaborated. Fortunately, other Dutch and Belgium PhD students have extensively elaborated on these topics in their research. For example, Cancer-related fatigue in older adults (Agasi-Idenburg, 2020), Decision making in geriatric oncology (Hamaker, 2012), and Colorectal (Schiphorst, 2014), Breast (De Glas, 2014; Van de Water, 2014), and Prostate cancer (Voerman, 2015) in older persons. This suggests that there appears to be no dearth of research on older adults at all. However, it should be noted that all these dissertations have been published within the last ten years, and some have a predominantly medical approach. As far as we know, there is only one dissertation that described an extensive range of common issues in older survivors with cancer, such as comorbidity, loneliness, psychosocial problems, and depression (Deckx, 2015). Despite the broad approach, the experiences of older adults with cancer themselves have not been investigated.

A final limitation – and strength at the same time – is the sole focus on older adults. Although we sometimes referred to studies on younger persons with cancer, we did not study this group of cancer patients and survivors ourselves. We are convinced that the focus on older people is well justified because of their large number, complexity, and underrepresentation in former studies. Nevertheless, comparison studies could provide more insight into the unique aspects of each age-group.

DIRECTIONS FOR FURTHER RESEARCH

These limitations lead to a number of recommendations for further research. More research is needed on subgroups of older people with cancer, such as older people of non-Dutch descent, cognitively impaired persons with cancer, the oldest old, and people in palliative or terminal phases. Furthermore, the experiences of family members can be studied to complement the experiences of older adults themselves.

Although older people in our studies reported high overall care satisfaction, it is useful to investigate whether satisfaction is really that high or whether other factors play a role. Older people are generally more inclined to follow the doctor's opinion and may be less likely to complain. Younger generations, including baby boomers, are more assertive and more adept at finding information on the Internet, which may result in a more critical stance towards the received care.

Because older persons with poor health, comorbid diseases, and limited social support, in particular, are at risk of not receiving the care and support they need, more attention should be paid to these people, both in clinical practice and in

research. When the duration of survival is expected to be limited, aspects related to quality of life become even more important. How, for example, spirituality can be of help to older adults in the palliative phase needs to be investigated further.

Sexuality, especially in older women, is an underexplored topic and needs to be studied to a greater extent as well. Furthermore, questions remain concerning the motivation of older men to join cancer support groups. Although most men with prostate cancer indicated that they had little need for support groups, they did appreciate spontaneous conversations about prostate cancer with fellow patients and medical professionals with whom they were friendly. Their potential interest in educational and/or social support groups requires more research, as well as potential forms this could take.

Last but not least, COVID-19 and its effect on older people with cancer is a very current topic that needs further study. We can only guess how delays in diagnosis and treatment will affect the course of cancer or how older persons will cope with the increased risk of illness and death, not to mention the social isolation and limited possibilities of social support. The current – and yet indefinable – situation may severely complicate the experiences of older persons with cancer, as well as the already complex care that is provided to them.

CONCLUSION

There are hopeful developments with regard to the study, treatment, and support of older people with cancer. Cancer care in the Netherlands is of a high standard, older people are predominantly satisfied with the care they receive, and more research in older adults with cancer is being conducted today than twenty years ago. However, the interest in older men and women with cancer still lags behind the attention paid to younger adults. This is worrisome because unknown often means unloved, whereas more and more health care professionals are needed to take care of this growing and heterogeneous group of people. A balanced and positive portrayal of older persons is therefore necessary. Sharing the stories of older people with cancer, perhaps even by themselves, can create greater insight and understanding of their lives and living conditions and motivate young professionals to work with this group. Personal preferences and quality of life need a more central place in the care of older adults. This care must be shaped as a joint responsibility of health care professionals and organisations, researchers, educational institutions, policy-makers, and eventually older adults themselves. Multidisciplinary care, so to speak, based on the premise that care is human-centred.

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