

### UvA-DARE (Digital Academic Repository)

### Friendship during patients' stable and unstable phases of incurable cancer

a qualitative interview study

Van Eijk, M.; De Vries, D.H.; Sonke, G.S.; Buiting, H.M.

DO

10.1136/bmjopen-2021-058801

Publication date 2022

**Document Version** Final published version

Published in BMJ Open License CC BY-NC

Link to publication

#### Citation for published version (APA):

Van Eijk, M., De Vries, D. H., Šonké, G. S., & Buiting, H. M. (2022). Friendship during patients' stable and unstable phases of incurable cancer: a qualitative interview study. *BMJ Open*, *12*(11), [e058801]. https://doi.org/10.1136/bmjopen-2021-058801

#### General rights

It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

#### Disclaimer/Complaints regulations

If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: https://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.

# BMJ Open Friendship during patients' stable and unstable phases of incurable cancer: a qualitative interview study

Michelle van Eijk, 1,2 Daniel H de Vries, 1 Gabe S Sonke, 3,4 Hilde M Buiting

To cite: van Eijk M, de Vries DH, Sonke GS, et al. Friendship during patients' stable and unstable phases of incurable cancer: a qualitative interview study. BMJ Open 2022;12:e058801. doi:10.1136/ bmiopen-2021-058801

Prepublication history for this paper is available online. To view these files, please visit the journal online (http://dx.doi. org/10.1136/bmjopen-2021-058801).

Received 30 October 2021 Accepted 17 February 2022

#### **ABSTRACT**

Objectives Little is known about the added value of friendship during the care of intensive cancer disease trajectories. Friends, however, can play an important (caring-)role to increase their friends' (mental) well-being. We explored the experiences and desires of friends while their ill friends were—most of the time—in a stable phase of incurable cancer.

**Design** Qualitative study in the Netherlands based on 14 in-depth interviews with friends of patients living with incurable cancer. Interviews were performed at the home setting or the friend's office. Data gathering was inspired by grounded theory and analysed with a thematic analysis. Setting The home setting/friend's office.

**Results** Friends reported to experience difficulties in how and how often they wanted to approach their ill friends. They emphasised the ever-present knowledge of cancer inside their friends' body as a 'time bomb'. They seemed to balance between the wish to take care for their ill friend, having a good time and not knowing what their ill friend desired at specific times. Some friends felt burdened with or forced to provide more care than they could, although they acknowledged that this relationship provided space to reflect about their own life.

Conclusions Friends are constantly negotiating and renegotiating their relationship depending on the severity of the disease, transparency of patients about their illness, their previous experiences and personal circumstances in life. Although a decrease in friendship may impact a patient's quality of life, friends also need to be protected against providing more care than they are willing or able to give. Healthcare professionals, being aware of this phenomenon, can assist in this.

#### INTRODUCTION

The palliative phase of cancer can be considered an intense period for patients as well as close relatives. <sup>12</sup> With new treatment options, a new disease phase has risen in which patients cannot be cured anymore, but in which the last phase of life is not approaching either.3 Often, patients can be physically quite fit, although they still have to deal with the ramifications of cancer. At present, the chronicity of (incurable) cancer is widely discussed in medicine. Interestingly, within anthropology, there was already an extensive body of literature and in which cancer was often referred to

#### STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ We did not provide any definition about friendship beforehand but let the patients choose who they considered to be friends (eg, family or non-family members) resulting in a valid study group of friends.
- ⇒ We interviewed more than one friend/family surrounding an ill friend, which enabled us to make comparisons across friends and put the qualitative data in context.
- ⇒ We only spoke with friends of patients treated from one single cancer hospital.
- ⇒ Results may be different in another hospital where patients' experiences with healthcare and healthcare professionals may be different.
- ⇒ We did not ask beforehand how long friends knew their friend already, which obviously may have influenced the results in how they spoke about their ill friend.

as a chronic illness.<sup>5</sup> It is for instance argued that 'the use of the term remission rather than cure already draws attention to cancer's chronicity'. In other words, chronicity of cancer lies in the uncertainty of remission at any moment as well as the mental, physical or social injury it may cause. At present, the chronicity of cancer is also widely discussed in the context of other chronic diseases.

The term 'chronic' in the context of incurable cancer receives increasing attention in the medical arena.<sup>8</sup> Dealing with dilemmas in the (medical) decision-making in this insecure disease phase appears to be a challenge for both the healthcare professional as well as the patient.<sup>8 9</sup> Although the label 'chronic' can be a relief for the patient, the differences across cancers bring along heated discussions among healthcare professionals. Patients being unsure about their prognosis, balance in preparing themselves for their approaching death and having a desire to live their life such as before their diagnosis of cancer. This disease phase therefore opens up new (unconscious and unmet) needs of patients and their close relatives in which



@ Author(s) (or their employer(s)) 2022. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by

For numbered affiliations see end of article.

#### **Correspondence to**

Dr Hilde M Buiting; hbuiting@gmail.com



social support, in the most broadest sense, could play an important role. The chronic nature of cancer thus may bring along challenges for friends also, since the disease trajectory is less clear and therefore may impact their relationship. The duration of a chronic disease, makes the impact on friendship compared with a short acute event more important.

Remarkably, limited literature about the socioemotional adjustment of patients living longer with incurable cancer exists. One study however suggests that patients with enduring diseases often experience a decrease in the number of friends and the frequencies of social contacts, even when not in an incurable cancer setting. With respect to friendship the amount of literature is even smaller, only very limited academic study has been done on the role of friendships for patients with cancer. This is surprising, since friendships have been shown to be a powerful healing force for physical and mental illness.

Friendship can be both harmonious and problematic, they are fluid as well as fixed, and individual as well as social.

The decrease of friendships may impact a patients' quality of life, since satisfying, fulfilling relationships play a major role in people's physical and emotional well-being. When the socially isolated women had an elevated risk of mortality compared with socially integrated women after diagnosis of breast cancer. Moreover, Taylor *et al*<sup>18</sup> showed that individuals experiencing support from close friends tend to live longer and remain healthier including a more positive outlook when faced with adversity. Is

The definition of friendship varies across disciplines but often accompanies the following elements: trust, communication and intimacy. 19 "I would rather walk with a friend in the dark, than alone in the light (Hellen Keller)" explicates the import role friendships can have. Both family members as well as non-family members can be considered as friends. Close relatives and family members may however, despite their natural bond with the patient, not regard themselves as a friend. In our study, family members who also considered themselves to be a friend, which is a voluntary decision, could be included. This volatile aspect is exactly what makes studying the impact of friendships towards quality of life of patients with cancer important. While the role of family members as informal caregivers has been acknowledged in the literature, <sup>20 21</sup> little is known about the added value of friendship relationships in the care for the patient (either as a family member or non-family member).

Experiences of friends themselves are lacking, and primarily focus on the patient perspective.  $^{15}$  <sup>22</sup> Given the lack of literature about the role of friendships, the potential important role of friends in supporting friends with incurable cancer, therefore warrants more exploratory research.

By interviewing friends about their ill friends, we aim to explore how friends experienced their friendships during stable and unstable phases of their ill friends confronted with incurable cancer.

# METHODS Design and setting

This study is part of a larger project that examines the experiences, needs and wishes of patients and healthcare professionals living longer with incurable cancer in the Netherlands. In this specific study, 14 interviews with friends (family and non-family) were conducted using a semi-structured qualitative interview approach, inspired by principles of grounded theory. (inductively) and analysed with a thematic approach (deductively). Data analysis started (almost) simultaneously with data collection, which continued to inform each other throughout the research process. This gave the process of data collection an iterative-inductive character.

In doing this, we verified the hypothesis as to whether friends could support their ill friends without experiencing such support as too burdensome for themselves. Thematic analysis was done by exploring the data with an open-minded approach, e.g., having no preconceived ideas beforehand in what could/should become the outcomes of the interviews that had been performed.

#### **Definitions**

The definitions about friendships vary. We purposefully chose to not use a specific definition about friendship but to leave this interpretation to the patient; we let them invite persons they themselves perceived as friends (see also 'Introduction' section). This approach was chosen because we wanted to explore how friendships were experienced during time-periods of patients with incurable cancer. Obviously, this can be best expressed by friends being perceived as friends by patients. That is why we chose for this exploratory approach in which both family as well as non-family members could be chosen. In about half of the cases, patients suggested family members ex-partners also—as friends. Although the bond of family members may be a little different compared with other people who consider themselves (and the patient) as friends, we all included them as friends in our sample. A previous study showed that in intimate/romantic relationships the friend part can be rather large as well.<sup>26</sup>

Apart from being a friend, friends can fulfill the role of an informal caregiver also. In this paper, we refer to an informal caregiver as someone providing some type of (usually) unpaid, ongoing assistance with activities of daily living or instrumental activities of daily living to a person with chronic illness or disability.

While we performed the interviews, we however took into account some baseline characteristics of friendship and social support. In general, good friends understand each other better and find each other easier to communicate. As a result, the relationships are in general rewarding and stable.<sup>27</sup> Friends may demonstrate



Table 1 Definiti	Table 1         Definitions frequently used in the field of medical anthropology				
Definition	Interpretation				
Friendship in sociology	Friendships have been defined at the macrolevel (eg, analyses of composition of friendship networks) and at the microlevel (eg, delineations of the features or characteristics of friendship relationships). Friendship has also been conceptualised in terms of the rules that friends are expected to follow and in terms of the expectations and standards that are held for this kind of relationship.				
Social network	Social relationships that constitute the social network—community organisations and systems through which support is mobilised and delivered.				
Sickness	Society's cultural and social values attributed to the physical malfunction of the body or patient. More specifically, the values that friends and family attribute to the disease of the patient.				
Care versus support	Care—contribution to one's physical and/or mental well-being. Support—voluntary incentive to encourage or contribute to the well-being of a patient.				
Support	A personal incentive and private form of encouragement to another person's well-being. The question whether it is support or not, is located in how the giver and recipient interpret and attribute meaning to support, rather than the objective characteristics attributed to it.				

immense faithfulness, dependability or responsibility towards one another, which can prove how deeply they value one another.

In table 1, we provide some definitions frequently used in the field of sociology/anthropology which have been used as a starting point of the analyses. This background information for instance helped us in formulating themes to increase understanding in how friendships were shaped in our sample.

#### **Data collection**

This study was performed in a comprehensive cancer centre in the Netherlands. In the period February 2018–May 2018, 14 in-depth semi-structured interviews were conducted. Twelve of the interviews took place in the home of participants, and two interviews took place at the office where the friends worked.

We recruited friends via patients that had previously been treated in the hospital. Since patients (previously being interviewed about their disease experiences<sup>8</sup>) were the starting point of data collection, all friends we recruited were linked to patients in one specific hospital. All patients were middle-aged, for example, between 40 and 70 years of age, and so were their friends. Those patients were not involved with the (content) of the interviews and they were not present during the interviews either. We made use of purposive sampling method, by approaching patients from the hospital.

All friends were sent an information sheet with the goals of the study and a consent form, beforehand. If consent was received, MvE, a female researcher in medical anthropology, approached the friends for an interview and formally agreed interviews via email. MvE previously performed different qualitative research projects as part of her study anthropology and so already gained some interview experience. Before MvE started an interview, friends signed an informed consent form. MvE did not know the patients beforehand. The median length of the audio-recorded interviews was 60 minutes.

Because all interviews were previously planned, all friends knew what they could expect because they had received an information sheet. We recruited 14 friends via 5 patients (see also table 2 for further explanation).

The interviews were semi-structured. By using a topic list, MvE tried to mention the same topics (sometimes illustrated with detailed example sentences) in every interview. This topic list was pretested with HMB. MvE always somewhere during the interview asked the general question: "What does cancer mean to you?" to get a little more grip in how patients experienced their disease.<sup>11</sup> Moreover, questions about how friends got to know their ill friend, previous personal experiences with cancer, issues that were considered particularly challenging, the frequency of visits to their friends, difficulties they experienced with their friends, whether they at a certain moment felt they were a caregiver (e.g, someone who need to take care of someone, instead of being a friend only) (in Dutch: mantelzorger), whether they experienced any rituals together with their friend, etc.

#### **Data analysis**

First of all, the interviews were coded in Word by MvE. In a later stage, all interviews were entered in Atlas-ti 8.2 by HMB, a female researcher in the field of palliative care and oncology, to analyse the data herself. Nine interviews were discussed twice at different time intervals to seek for themes (MvE, HMB). These themes were discussed to check for interpreter consensus. Subsequently, a scheme was developed to index text fragments with similar content. Simultaneously, by analysing the data, principles of grounded theory were used, for example, data analysis started (almost) simultaneously with data collection, which continued to inform each other throughout the research process.<sup>24</sup> The process of data collection accordingly resulted in an iterative-inductive character. 25 Initial data were analysed to look for emerging themes, which in turn informed the content of upcoming interviews. It means that analysing the data thematically, and using

Patient	Friend	Gender	Relationship	Place/Other
A	1	F	Daughter-in-law†	Home
	2	F	Friend	Home
	3	F	Friend	Home
	4	F	Ex-daughter-in-law† Friend	Home
	5	М	Ex-husband† Friend	Home
В	6	F	Sister†	Home
	7	F	Friend	Home
	8	F	Stepdaughter†	Home
С	9	F	Friend	Home
	10	M	Partner†	Office
	11	F	Friend	Office
D	12	M	Friend	
Е	13	F	Friend	Home
	14	F	Partner†	Home

<sup>\*</sup>Names are pseudonyms to protect our informants.

†Although we asked patients whether they would invite *friends* to participate in this survey, in half of the cases they suggested family members (even the partner) as friends. Since this is how these patients regarded this relationship, we did include all of them in this study. F, female; M, male.

grounded theory went hand in hand. The discovery of theory from data (eg, grounded theory) is a major task confronting sociology, for such a theory fits empirical situations, and is understandable to sociologists and laymen alike. During the analysis, all hypotheses that we formulated were checked with the data (HMB and MvE). Interviews were stopped after data saturation was reached. This is the moment no new information are mentioned by the participants (friends) in relation to the research questions as have been posed in the 'Introduction' section.

We all evaluated whether the final quotes were used in the right context. Transcripts were not returned to the friends. All transcripts were audio-recorded and transcribed; all of the names are pseudonyms; several items to ensure adequate qualitative research were checked with the Consolidated criteria for Reporting Qualitative research checklist, which is of course not a guarantee of the quality of the research itself.<sup>28</sup>

#### Patient and public involvement

We did not involve friends to collaborate in the interpretation of the study findings; we however send them a lay version of the summary of the findings.

#### **RESULTS**

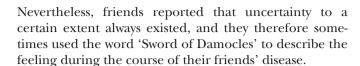
This study included 14 friends, 7 of them were family members. We interviewed 11 women and 3 men, with an average age of 50 years; 11 friends had children, 13 friends had a partner. None of the friends refused to participate. In one interview, the partner of the friend was present during the interview as well.

#### **Interview findings**

We identified three domains that provided deepened insight about the experiences and the perceived role of friends during the incurable phase of cancer: (1) cancer as threat and inspiration, (2) a patient or friend and (3) support.

### Cancer as threat and inspiration

Our friends reported that the disease trajectory their ill friends were in placed an urgency on the time that was still available to spend with each other. This degree to which such temporality was experienced, influenced the way in which friends approached their ill friend. If their ill friends did not have to wait for news from the hospital, some friends also reported to feel less urgency to visit their ill friend and/or invest in the relationship.



[...] then I am sitting here with the thought that maybe soon she has to say goodbye to us, how are we going to do that? And that is constantly in your head. Because I mean, now everything is fine, but this can be different next year. So, how are we going to do that? Participant 6 (Patient B), family related friend

Friends for whom this was their first experience with cancer or who had no prior experience with healthcare, sometimes reported to experience an intense feeling or pressure on the contact they were having with their friend. The nature of their friendship and living situation seemed to determine to what extent this feeling developed into a sense of urgency or pressure in their friendship. For friends who lived far away from their ill friend, some reported that the Sword of Damocles could also take away some spontaneity and creativity, which sometimes resulted in a lower frequency of visits. Friends reported that they did not think of this Sword constantly or daily but somewhere in the back of their head, they acknowledged that it would always be a possibility that this threat would become very real.

So you've noticed: I am not living close to Sarah, so when I go there to visit her, it's not for an hour to drink a cup of coffee, and that is what makes it difficult. And if I would live closer I would visit more frequently and then there would be a bit more air between us as well [...] but then there is this constant idea of the Sword of Damocles... Participant 4 (Patient A) family related friend

During all interviews, it became clear that the experiences friends had with their ill friends had also left its prints on their personal ideas about cancer. Initially, most friends spoke about cancer with fear and anxiety. However, during interviews they at the same time expressed how it inspired them and how it had made them reconsider their own life or relationships in a more positive perspective. The intensity of their friends' suffering and the way their friends coped with their disease was expressed as providing a sense of pride and respect towards their ill friend.

Yeah it's like I said, you get inspired by it. If you see her conditions and how she manages to still see light at the end of the tunnel, that's just very impressive. Participant 2 (Patient A), family related friend

Apart from the threat they experienced for their ill friend, they also felt a threat themselves as in how they experienced uncertainty. For friends, their ill friends represented the embodiment of insecurity and threat to existence. It at the same time represented empowerment as the illness of friends made them learn a lot of their own strengths in dealing with and accepting adversity. Some

friends indirectly seemed to mention that this motivated friends to stay engaged with their ill friends.

Well, you have a certain confidence in life, for example: I'm going to grow old and die at one point. I mean you know that everybody dies at some point, but that it is still very far away. Participant 13 (Patient E), family related friend

#### A patient or friend

Apart from the threat that friends themselves experienced, friends also reported to sometimes struggle with the idea that their ill friend, is a *patient* suffering from cancer. Often, the long periods in which patients were in a stable disease phase, this disease phase was somewhat overshadowed while focusing on the (seemingly) good condition of the patient. However, viewing their friend for a longer time, they sometimes realised they were more ill than expected.

So, we see each other like one or two times a month for about two hours, or we go out for dinner, we sometimes do that. And then you have some distraction and other things you can talk about. And you know, we are full of energy and she is full of energy, because she has prepared herself for this activity or that dinner. Participant 8 (Patient B), stepdaughter

Friends reported that increased feelings of a Sword of Damocles, such as less fortunate messages on the progression of the disease, witnessing bodily pains, restrains in ability for certain activities, or spending a longer amount of time with them regardless of circumstances, they more easily referred to them in terms of 'patient'. When communication between members of the social network and patient was good, or when they had experiences with the disease due to their type of work or prior experiences with close friends or family, they would refer to the patient more in terms of the 'person'.

Both emotions: guilt and powerlessness as well as manifestations of gratitude and appreciation were shown by the friends. Sometimes, friends stated that they felt guilty when they had the feeling that they did not engage enough or felt they did not adhere enough to the needs of the patient. Many friends reported to be thankful for their friendship, but the extended disease phase sometimes complicated certain matters of their friendship. In other words, certain conversations, like talking about future plans or decisions, work or outward appearance would force friends to reconsider their relationship more in terms of 'patient' than 'person'. Moreover, some friends reported that mutual expectations of one another could be imbalanced, now experiencing a *forced* relationship.

I think that when I would start to share all these stories with her [ of other friends with cancer] just for the sake of her having the same condition... and imagine everyone sharing their stories about other ill people with her, just because she has the same condition as them; That would be unhelpful.

It would appear to me as very tedious when people would share all these stories with me just because I would have the same illness, and also irrelevant. Neither would I keep such stories from her though, because that would seem inappropriate as well. (...)

You know, I don't see her as a patient when I want to talk to her about other friends or acquaintances with cancer, she is a friend to whom I speak at that moment. Participant 11 (Patient D), friend

#### Support

All friends reported to try to give some 'personal' form of support. However, support was demonstrated in different manners, although all with the same function: to encourage their friends' well-being. One friend for instance supported her ill friend during heavy chemotherapy sessions:

So the last time she was very ill, every day I would send her a link with a certain piece of classical music that I picked out for her. It was like a ritual really. Because at night she couldn't sleep, and then she would listen to the music I had picked out for her. Participant 3 (Patient A), friend

The extent to which a patient was transparent about their own emotions influenced the amount and type of support of friends. Not everyone provided support in the same and equal amount, implying that the expectation within the relationship they had with one another differed. Apart from practical support, another common, but personalised, way of support was through regular conversation. Deeper conversations allowed space to inform about each other's well-being and to contribute to it by showing their affection by way of being attentive to each other's whereabouts, feelings and stories. Such support was also possible for friends living farther away. This 'being there' seemed to reflect a certain kind of generality—I am here for you—a seemingly spiritual and emotional mode of support; it is unknown where the 'here' is located and what it exactly entails.

I: Do you have the idea that you take care of her, or support her?

R: Yeah it's a bit of a difficult situation because I live so far away. I would love it, if hypothetically I would live close to her, to do a lot of things for her. That is very frustrating. So support is purely mental and from a distance. Participant 4 (Patient A), friend

During the interviews, it became clear that the most important difference between those who are family or not is that friends do not *have* to care for their ill friends as family usually is used to be. Responsibility to one

another in the family context claims a certain expectation of care on the members of a family, whereas friendship alone eludes this role/responsibility. While some family members reported to experience care as a source of stress, for friends, due the voluntariness of the act, care contributed to the strength of their friendship. The nonfamily friends seemed to translate care in the support and concern for the patients' well-being, such as offering help in practical situations. Friends further indicated that there was a great difference to the way they interacted with their ill friend depending on if they had a partner or not. If not, friends and family members were more concerned and wanting to stand by their ill friend.

R: The amount of care I provide for her is very limited, but I do have a sense of concern for her, at least that is how I feel it. [...] She lives alone. And it also comes from a basic instinct, or feeling, that we have had for each other.

I: Also a sense of responsibility?

R: No, a sense of responsibility feels too strong for me. I am not responsible for either her or her situation. But I want to stand by her and help her in this situation. Participant 5 (Patient A), family-related friend

This contrasted with what some other more direct family members experienced. Since, when there is a partner, they would naturally take over a considerable part of the care demand. Some of the friends felt burdened with or forced in providing more care than they were willing to provide. Nevertheless, friends also indicated that there might be circumstances to step in more than they were initially willing to at some point. They acknowledged that there is always a possibility of support translating into care when circumstances demand such a shift. However, friends noted that it is in this *possibility* that lies the tricky part for friends-that is to say, they actively seemed to negotiate the extent of their support, and tried to find balance in what they can give, what they themselves received, and what they need to reserve for other relationships in their lives.

You know, the way you go about these things really depends on the person across from you, and subsequently the way you can help them. But all these things take time, and I also want to continue to do my own things, I want to have some energy left. Participant 3 (Patient A), friend

#### **DISCUSSION**

This study showed that friends are constantly negotiating and renegotiating their relationship with their ill friend depending on the severity of the disease, their experiences with previous patients with cancer and personal circumstances and desires in life. The uncertain development of a disease trajectory of living longer with incurable cancer placed an urgency and uncertainty on the time

available to spend with each other. The degree to which this urgency was experienced ('Sword of Damocles'), influenced the way in which friends approached their ill friends. Moreover, the capacity to stay socially connected with their ill friends was also determined as to whether they also functioned as family members/partners. Although care was in general voluntary, some friends that were included in this study felt burdened with or forced in providing more care than they were willing to provide.

#### Positive effects of having an ill friend

Our study showed how friends experience urgency with and through their friends because of the incurable nature of the disease. Although literature in the field of uncertainty regarding prognosis for patients and healthcare professionals is substantial, 2 29 information about the effect for and on friends is-to the best of our knowledge-absent. The uncertainty friends themselves experienced, determined, in part, their view on cancer as sickness on the one hand, while on the other hand motivated a self-reflexive perspective on their own life and relationships.<sup>26</sup> Witnessing the bodily and mental suffering that their friends had to endure, associated cancer with anxiety, pain and suffering. Witnessing the attitude and actions of the patient in coping with their disease, embodied hope, inspiration, gratitude and appreciation in their own life. This ambivalence in their relationship empowered them to live their own life fully, and at the same time created a good relationship with their sick friends. Our finding that friends benefit themselves from those relationships during these intense periods in their personal life, may sometimes stimulate the continuation of friendships when friends become ill even further. This is an important finding as many studies have shown that friendships decrease in frequency when patients are diagnosed with cancer, partly because friends are afraid and do not know how to approach their ill friends.<sup>30</sup>

#### The healthy patient, the ordinary friend

If, however, friends stayed in contact with their ill friends, a substantial proportion of friends in our study also preferred to do joyful things with their ill friend. In other words: they did not consider it as a (social support) burden per se. This is in line with previous studies that show that friends attribute relatively low importance to the role of caregiving in the role of friendship (3% as opposed to spouses 66%, offspring 17%, siblings 7% and parents 40%)<sup>21 31</sup> as was reported in a review by Romito et al.<sup>32</sup> However, having cancer, receiving treatment and suffering from the side effects of treatment can have a tremendous effect on social bonding.<sup>33</sup> It goes without saying that patients are less able to do the joyful things they were used to do before. Our study nevertheless showed that patients in this protracted disease phase often seemed seemingly healthy and accordingly could often behave as 'normal' friends also.

Patients may nevertheless have become isolated from normal activities/work, partly because they could not share their cancer experiences.<sup>34</sup> Our study showed that sometimes a relationship seemed to change when difficult topics were brought up or when physical problems hindered them in doing social activities. It thus seems that at least part of the friends in this study approached their ill friends only when they were in seemingly good condition. Possibly, a balancing of seeing the 'other' in this friendship relationship in terms of 'patient' versus 'friend' was different as this seemed to be regarded as less equal and accordingly felt uncomfortable for the friend (and possibly patient) concerned. This negotiating and renegotiating the other as patient or person is an important finding because the way that friends perceived a patient as in fact 'patient' or 'person' could influence the way we behave towards patients in terms of care and support.

# (Social) distance during stable and unstable phases of incurable cancer

Our study showed that friends living farther away felt less able to care for the patient, because they could not 'drop by' easily.35 The caring role they sometimes might want to provide as a friend therefore sometimes disappeared. Interestingly, all friends (interviews were taken during a pre-COVID-19 time-period) never spoke about other ways of contact (eg, telephone or online meetings) than face-to-face. Probably, other contacts are experienced as less impactful than face-to-face contact. During a COVID-19 period, where online contact has become far more important, it is relevant to know that differences between friends living close by versus living farther away have become less important. The psychosocial burden of the pandemic on patients with cancer, with additional fears and loneliness has previously been shown.<sup>36</sup> A report focusing on social distance problems among vulnerable groups in the Netherlands during COVID-19, showed—among other things—that COVID-19 had a substantial impact on the elderly with one out of seven experiencing loneliness and a substantial increase in mood and behaviour problems.<sup>37</sup> These findings with respect to friendship can help to better understand how friendship can stay alive during COVID-19, for example, during tough times.<sup>38</sup>

#### **Strengths and limitations**

A feature that increases the validity of this study is that we followed patients' suggestions of friends and did not provide any definition about friendship beforehand. As a result, we also included family members (also labelled as friends). The fact that patients provided us the names of these family members, shows that they trusted these family members sufficiently to let them talk about their disease. Moreover, none of the family members approached were surprised to be approached as a friend. It however could also mean that patients lost some friends outside a family context and accordingly

mentioned more family members as friends. Another feature is that we often interviewed more than one friend/family member surrounding an ill friend, which enabled us to make comparisons and put the qualitative data in context. Although we did not include this information explicitly (anonymity), this increased our understanding substantially.

Our study however also has limitations. First, because we gave no definition of friends beforehand, we also introduced some bias since the introduction of family and non-family members resulted in a limited number in each group which could have introduced some bias. Second, from an anthropological perspective this study included a lack of spontaneity. There were no casual conversations on the topic as one might encounter in a field that is a place where people are constantly together. Second, we only spoke with friends of patients from one single cancer hospital. Results may be different in another hospital where experiences with healthcare and healthcare professionals may be different. Third, we only held one single interview with every friend. A longitudinal perspective might be interesting as experiences of friends to a large extent seem to differ depending on the disease status of their ill friend and personal circumstances. Fourth, our results showed that friends living farther away from the patient had different and less frequent contact than friends living close by. These differences are relevant from a COVID-19 perspective also, where friends living close by cannot (or to a limited extent only) visit the patient. Fifth, we did not ask beforehand how long friends knew their friend already, which obviously may influence the results. Sixth, all friends were middle-aged, it may well be possible that younger patients have a different definition of friendship than people of higher age. Finally, we did not systematically collect information about the friends' mood and their family life (including previous experiences with cancer), which might have influenced the results.

#### **Conclusions and implications for health policy**

Our study showed that friends, being a non-family member, experienced no expectations of a responsibility with respect to care giving, and if there was, this remained a voluntary one. This reciprocal aspect of support through these friendship relationships seems one reason why friends provide support in a different way than for instance healthcare professionals do. For friends, being a family member also, more struggles and negativity could be experienced because they did not always want to provide such support themselves. Nevertheless, by providing their support, love and hope, friendship may benefit both themselves as well as their ill friends. The interesting finding that friends appreciated those contacts, precisely because it also assisted them in better reflecting about their own life was an unexpected finding. This is however noteworthy since this will facilitate and put the sometimes

burdensome contacts with their ill friends in perspective. In future research it would be worthwhile to distinguish different types of friends, since family members also have different roles, and this could overlap with their role as a friend.

Our study showed that inclusiveness and openness towards each other about the patient's and friends' feelings deserves further attention. This can for instance be done by making patients aware to also include their friends in their illness process to maintain beneficial (equal) relationships that may contribute to the patient's and friends' emotional and physical wellbeing. In doing so, support provided by friends should be personalised and on a voluntary basis.

Finally, our study shows the role friends choose for themselves and how this may facilitate patients in improving their well-being. This is a relevant finding in the context of supportive care in the growing group of patients with some form of incurable cancer.

Being aware of the important effect of friendships in either a medical or private setting is rather important. It shows how (being a family member or not) friends can support patients/people in difficult times. This 'mental' support can have a tremendous effect on patients'/people quality of life and mental well-being, and this definitely warrants further attention. Supporting such relationships, as a healthcare professional, warrants attention. Supporting such relationships through healthcare professionals or other groups of society need to be further studied.

#### Author affiliations

<sup>1</sup>Faculty of Social and Behavioural Science, Department of Sociology and Anthropology, University of Amsterdam, Amsterdam, The Netherlands <sup>2</sup>Netherlands Cancer Institute / Antoni van Leeuwenhoek, Amsterdam, The Netherlands

<sup>3</sup>Department of Medical Oncology, Antoni van Leeuwenhoek/Netherlands Cancer Institute, Amsterdam, The Netherlands

<sup>4</sup>University of Amsterdam, Amsterdam, The Netherlands

<sup>5</sup>Antoni van Leeuwenhoek/Netherlands Cancer Institute, Amsterdam, The Netherlands

<sup>6</sup>University Medical Center Utrecht, Utrecht, The Netherlands <sup>7</sup>02PZ Platform of Palliative care, Amsterdam, The Netherlands

**Acknowledgements** We thank all patients and their friends who cooperated to make this interview study possible. We further thank Jan Schildmann for his comments on a previous version of this manuscript.

Contributors HB designed the study. MvE carried out the study. MvE, HB, DdV and GS were involved in the interpretation of the study findings. MvE and HB wrote the manuscript which was critically read by all the authors. HB is guarantor of the study. All authors had full access to all the data in the study and can take responsibility for their integrity and the accuracy of their analysis.

**Funding** This study was funded by Janssen Research and Development and Ars Donandi.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Consent obtained directly from patient(s).

Ethics approval An extensive ethical review was not deemed necessary by the hospital review committee (Antoni van Leeuwenhoek), and the ethical committee provided us with a declaration of no objection (P15CHR) after having seen the



research protocol of the study. During the study, we however asked for informed consent for every study participant, and all data were analysed anonymously.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement There are no additional data available. However, if there will be questions surrounding certain quotes, we will be happy to answer these

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: http://creativecommons.org/licenses/by-nc/4.0/.

**Author note** We previously presented some of these results in an abstract for the NCRI. The content of this abstract (no oral presentation was held) was similar to the abstract as submitted to BMJ Open.

#### **ORCID ID**

Hilde M Buiting http://orcid.org/0000-0001-6557-6906

#### **REFERENCES**

- Buiting HM, Terpstra W, Dalhuisen F, et al. The facilitating role of chemotherapy in the palliative phase of cancer: qualitative interviews with advanced cancer patients. PLoS One 2013;8:e77959.
- 2 Mack JW, Smith TJ. Reasons why physicians do not have discussions about poor prognosis, why it matters, and what can be improved. J Clin Oncol 2012;30:2715–7.
- 3 Buiting HM, Linn SC, Smorenburg CH, et al. [Living with incurable cancer]. Ned Tijdschr Geneeskd 2016;160:A9615.
- 4 Harley C, Pini S, Bartlett YK, et al. Defining chronic cancer: patient experiences and self-management needs. BMJ Support Palliat Care 2015;5:343–50.
- 5 Petryna A. Health: anthropological aspects; 2015.
- 6 Smith-Moris M, Smoth-Moris L, Smith-Moris C. Introduction: chronicity and the experience of illness. Chronic Conditions: Fluid States: Chronicity and the Anthropology of Illness: Rutgers University Press, 2010.
- 7 Holland JC. History of psycho-oncology: overcoming attitudinal and conceptual barriers. *Psychosom Med* 2002;64:206–21.
- 8 Buiting HM, van Ark MAC, Dethmers O, et al. Complex challenges for patients with protracted incurable cancer: an ethnographic study in a comprehensive cancer centre in the Netherlands. BMJ Open 2019:9:e024450.
- 9 Buiting HM, de Bree R, Brom L, et al. Humour and laughing in patients with prolonged incurable cancer: an ethnographic study in a comprehensive cancer centre. Qual Life Res 2020;29:2425–34.
- 10 Buiting HM, Bolt EE. Patients with incurable cancer as a separate group of survivors in the primary care setting. Cancer 2019;125:4541.
- 11 Salas CE, Casassus M, Rowlands L, et al. "Relating through sameness": a qualitative study of friendship and social isolation in chronic traumatic brain injury. Neuropsychol Rehabil 2018;28:1161–78.
- 12 Dawson DR, Chipman M. The disablement experienced by traumatically brain-injured adults living in the community. *Brain Inj* 1995;9:339–53.
- 13 Arora NK, Finney Rutten LJ, Gustafson DH, et al. Perceived helpfulness and impact of social support provided by family, friends, and health care providers to women newly diagnosed with breast cancer. Psychooncology 2007;16:474–86.

- 4 Evans R, Mallet P, Bazillier C, et al. Friendship and cancer. Rev Health Care 2015, 2015;6:53–65
- 15 Dressler WW, Balieiro MC, Dos Santos JE. The cultural construction of social support in Brazil: associations with health outcomes. *Cult Med Psychiatry* 1997;21:303–35.
- 16 Fehr B. Chapter: The role of friendships in well-being. In: Subjective well-being and life satisfaction. New York, US: Routledge/Taylor & Francis Group, 2018.
- 17 Kroenke CH, Kubzansky LD, Schernhammer ES, et al. Social networks, social support, and survival after breast cancer diagnosis. J Clin Oncol 2006;24:1105–11.
- 18 Taylor SE, Falke RL, Shoptaw SJ, et al. Social support, support groups, and the cancer patient. J Consult Clin Psychol 1986;54:608–15.
- 19 Claes M, Poirier L. [Characteristics and functions of friendship in adolescence]. Psychiatr Enfant 1993;36:289–308.
- 20 Kim Y, Schulz R, Carver CS. Benefit-finding in the cancer caregiving experience. *Psychosom Med* 2007;69:283–91.
- 21 Kim Y, Spillers RL, Hall DL. Quality of life of family caregivers 5 years after a relative's cancer diagnosis: follow-up of the National quality of life survey for caregivers. *Psychooncology* 2012;21:273–81.
   22 Dressler WW, Balieiro MC, Ribeiro RP, *et al.* Culture and the immune
- 22 Dressler WW, Balieiro MC, Ribeiro RP, et al. Culture and the immune system: cultural Consonance in social support and C-reactive protein in urban Brazil. *Med Anthropol* Q 2016;30:259–77.
- 23 The AM, Koëter G, Koëter G, et al. Collusion in doctor-patient communication about imminent death: an ethnographic study. BMJ 2000;321:1376–81.
- 24 Glaser B, Strauss A. The discovery of grounded theory: strategies for qualitative research. Chicago: Aldine, 1967.
- 25 Green J, Thorogood N. Qualitative methods for health research. London: Sage, 2004.
- 26 Perel E. Mating in captivity. Publisher HC, 2007.
- 27 Veenstra R, Dijkstra JK, Steglich C, et al. Network-Behavior dynamics. J Res Adolesc 2013;23:399–412.
- 28 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19:349–57.
- 29 Raskin W, Harle I, Hopman WM, et al. Prognosis, treatment benefit and goals of care: what do oncologists discuss with patients who have incurable cancer? Clin Oncol 2016;28:209–14.
- 30 Wijnhoven MN, Terpstra WE, van Rossem R, et al. Bereaved relatives' experiences during the incurable phase of cancer: a qualitative interview study. BMJ Open 2015;5:e009009.
- 31 Kim Y, Kashy DA, Kaw CK, et al. Sampling in population-based cancer caregivers research. Qual Life Res 2009;18:981–9.
- 32 Romito F, Goldzweig G, Cormio C, et al. Informal caregiving for cancer patients. Cancer 2013;119 Suppl 11:2160–9.
- 33 Einberg E-L, Svedberg P, Enskär K, et al. Friendship relations from the perspective of children with experience of cancer treatment: a focus group study with a salutogenic approach. J Pediatr Oncol Nurs 2015;32:153-64
- 34 Nicholas DB, Darch J, McNeill T, et al. Perceptions of online support for hospitalized children and adolescents. Soc Work Health Care 2007;44:205–23.
- 35 van Alphen E, Campmans X. Living (longer) with incurable cancer; 2020.
- 36 Schellekens MPJ, van der Lee ML. Loneliness and belonging: exploring experiences with the COVID-19 pandemic in psychooncology. *Psychooncology* 2020;29:1399–401.
- 37 de Vries D, Pols J. [In Dutch] Effecten van sociale afstand op kwetsbare groepen in Nederland. Amsterdam: University of Amsterdam, 2020.
- 38 Garutti M, Cortiula F, Puglisi F. Seven shades of black thoughts: COVID-19 and its psychological consequences on cancer patients. *Front Oncol* 2020;10:1357.