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## Friendship during stable and unstable phases of incurable cancer.

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## Friendship during stable and unstable phases of incurable cancer

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### Running title

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The authors thank all patients and patients' friends who participated in this study. We further 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.

### Keywords

Friendship, oncology, prolonged incurable cancer

### Word count

4600

### Strength and limitations

- We did not provide any definition about friendship beforehand but let the patients choose who they considered to be friends (e.g. 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 from one single cancer hospital. Results may be different in another hospital where 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
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**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

**Results:**

Friends reported to experience difficulties in how and how often they wanted to approach their ill friends. They emphasized 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 patients' quality of life, friends also need to be protected against providing more care than they are willing or able to give.

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## INTRODUCTION

The palliative phase of cancer can be considered an intense period for patients as well as close relatives. (1, 2) 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. (4) At present, the chronicity of 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 as a chronic illness. (5) Manderson and Smith-Morris (2010) for instance argue that “the use of the term *remission* rather than *cure* already draws attention to cancer’s chronicity”. (6) 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. (7)

Currently, the term ‘chronic’ in the context of incurable cancer receives increasing attention in the medical arena. (8) Dealing with those dilemmas in such an insecure disease phase appears to be a challenge for both the healthcare professional as well as the patient. (8, 9) Although the label chronic can be a relief for the patient, the differences across cancers bring along heated discussions among healthcare professionals. Patients have been shown to experience dilemmas, particularly because they are unsure about their prognosis, balancing in preparing themselves for their approaching death and having a desire to live their life such as before their diagnosis of cancer. (10) This disease phase therefore opens up new (unconscious and unmet) needs of patients and their close relatives in which social support, in the most broadest sense, could play an important role.

Remarkably, limited literature about the socio-emotional adjustment of patients during this (protracted) disease phase of cancer exists. (11) One study however suggests that patients with enduring diseases often experience a decrease in the number of friends and the frequencies of social contacts. (12, 13) 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 cancer patients. (14) 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. (15) (14, 16) Kroenke *et al* (2006) for instance showed that socially isolated women had an elevated risk of mortality compared to socially integrated women after diagnosis of breast cancer. (17) Moreover, Taylor *et al* (1986) showed that individuals experiencing support from close friends tend to live longer and remain healthier including a more positive outlook when faced with adversity. (18)

The definition of friendship varies across disciplines but often accompanies the following elements: Trust, communication and intimacy. (19) Both family members as well as non-family members can be considered as friends, and an overarching quote such as ‘I would rather walk with a friend in the dark, than alone in the light (Hellen Keller)’ explicates the import role friendships can have. Close relatives and family members may already have a natural bond with the patient but do 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 on cancer patients’ quality of life important. While the role of family members as informal caregivers has been acknowledged in the literature (20, 21), 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, 22) Given the lack of literature about the role of friendships, the potential important role of friends in supporting people with advanced cancer – this warrants more research.

### Research questions

- (1) What kind of support do friends provide?
- (2) Do friends struggle to provide it?
- (3) How do they view their role during this time-period?

With such an approach we aim to obtain a broad overview of all possible ways friendships developed throughout the disease course, and was experienced.

## 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. (8, 23) In this specific study, 14 interviews with friends (family and non-family) were conducted using a semi-structured qualitative interview approach, inspired by grounded theory (inductively) and analyzed with a thematic approach (deductively). In doing this, we verified the hypothesis as to whether friends supported their ill friends without viewing this as too burdensome for themselves. Thematic analysis was done by exploring the data with an open-minded approach, having no preconceived ideas beforehand in what would be 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**). 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 to 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.(26)

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.(27) Friends may demonstrate immense faithfulness, dependability or responsibility toward 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, e.g. this background information helped us in the formation of themes to understand how friendships were shaped in this sample.

[Table 1 about here]

### Data collection

This study was performed in a Comprehensive Cancer Centre in the Netherlands. In the period February 2018 – May 2018 fourteen 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 (a Dutch comprehensive cancer centre). Since patients (previously being interviewed about their disease experiences (8)) were the starting-point of data collection, all friends we recruited were linked to patients in one specific hospital. 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). None of the friends refused to participate. In one interview, the partner of the friend was present during the interview as well.

[Table 2 about here]

The interviews were semi-structured. By using a topiclist, MvE tried to mention several topics (sometimes illustrated with detailed example sentences) in every interview. This topic list was pretested with HMB. She 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>1</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 (In Dutch: *mantelzorger*), whether they experienced any rituals together with their friend, et cetera.

### Data Analysis

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3 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  
4 HMB, a female researcher in the field of palliative care and oncology, to analyse the data herself. Nine interviews  
5 were discussed twice at different time intervals to seek for themes (MvE, HMB). These themes were discussed to  
6 check for interpreter consensus. Subsequently, a scheme was developed to index text fragments with similar  
7 content. Simultaneously, by analysing the data, principles of grounded theory were used, e.g. data analysis started  
8 (almost) simultaneously with data collection, which continued to inform each other throughout the research  
9 process.(28) The process of data-collection accordingly resulted in an iterative-inductive character.(29) Initial data  
10 was analyzed to look for emerging themes, which in turn informed the content of upcoming interviews. It means  
11 that analysing the data thematically, and using grounded theory went hand in hand. The discovery of theory from  
12 data (e.g. grounded theory) is a major task confronting sociology, for such a theory fits empirical situations, and is  
13 understandable to sociologists and laymen alike. During the analysis, all hypotheses that we formulated were  
14 checked with the data (HMB and ME). Interviews were stopped after data saturation was reached. This is the  
15 moment no new information are mentioned by the participants (friends) in relation to the research questions as  
16 have been posed in the introduction section.

16 We all evaluated whether the final quotes were used in the right context. Transcripts were not returned to the friends.  
17 All transcripts were audio-recorded and transcribed; All of the names are pseudonyms; Several items to ensure  
18 adequate qualitative research were checked with the COREQ-checklist, which is of course not a guarantee of the  
19 quality of the research itself. (30)

### 20 **Ethics**

21 An extensive ethical review was not deemed necessary by the hospital review committee (Antoni van  
22 Leeuwenhoek), and the ethical committee provided us with a declaration of no objection (P15CHR) after having  
23 seen the research protocol of the study. During the study we however asked for informed consent for every study-  
24 participant, and all data were analyzed anonymously.

### 25 **Public and patient involvement**

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

### *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. Nevertheless, friends reported that uncertainty to a certain extent always existed, and they therefore sometimes used the word 'Sword of Damocles' to describe the feeling during the course of their friends' disease.

*[...] 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? Yvette [Patient B, participant 6, family-related friend]*

Friends for whom this was their first experience with cancer or who had no prior experience with health care, 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... Megan (Patient A, participant 4, family-related friend)*

During all interviews it became clear that the experiences friends had 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, at the same time, they 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. [...] Look, cancer has influence on me in the way that it makes me aware of my blessings. Alice (Patient A, participant 2, 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. With her [Hestia] there hangs this... even though sometimes I forget, but I am occasionally reminded of it. Livia (Patient E, participant 13, 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 friend, the patient, is a *patient* suffering from cancer. Often, the long periods in which patients were in a

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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 realized they were more ill than expected.

Friends reported that increased feelings of a Sword of Damocles, such as less fortunate messages on the progression of the disease, witnessing bodily pains, restraints 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 had experiences

*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. And so this one time, we went away for the weekend, and then you realize: Gee, she walks a bit strange and her balance is off [...] and then you realize: Jesus she is in worse shape than I thought." Yasmine*

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'. The prolonged time span sometimes resulted in situations where being sick and the 'sick role' escaped the consciousness of the social network.

Both emotions: Guilt and powerlessness as well as manifestations of gratitude and appreciation were shown by the friends. Sometimes, friends stated that they would feel 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 topic 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 [of other people with cancer] with her just for the sake of her having the same condition... and imagine everyone sharing their stories on other 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. But yeah, I do think that I make certain choices because of it, although I don't consider that to be a bad thing. Otherwise I would not do it like that haha.*

## Support

All friends reported to try to give some 'personal' form of support. However, support was demonstrated in different manners, albeit 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. Alana (Patient A, participant 3, 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 personalized, 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. Megan (Patient A, participant 4, 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,

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3 due the voluntariness of the act, care contributed to the strength of their friendship. The non-family friends seemed  
4 to translate care in the support and concern for the patients' well-being, such as offering help in practical situations.  
5 Friends further indicated that there was a great difference to the way they interacted with their ill friend depending  
6 on if they had a partner or not. If not, friends and family members were more concerned and wanting to stand by  
7 their ill friend.

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9 *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.*

10 *I: Also a sense of responsibility?*

11 *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.*

12 *Hugo (Patient A, participant 5, family-related friend)*  
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16 This contrasted with what some other more direct family members experienced. Since, when there is a partner,  
17 they would naturally take over a considerable part of the care demand. Some of the friends felt burdened with or  
18 forced in providing more care than they were willing to provide. Nevertheless, friends also indicated that there might  
19 be circumstances to step in more than they were initially willing to at some point. They acknowledged that there is  
20 always a possibility of support translating into care when circumstances demand such a shift. However, friends  
21 noted that it is in this *possibility* that lies the tricky part for friends – that is to say, they actively seemed to negotiate  
22 the extent of their support, and tried to find balance in what they can give, what they themselves received, and what  
23 they need to reserve for other relationships in their lives.

24 *You know, the way you go about these things really depends on the person across from you, and subsequently  
25 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  
26 to have some energy left.* *Alana (Patient A, participant 3, friend)*  
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## 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 cancer patients, 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.

### *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-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. 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.

### **Ambivalence**

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, 31), 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.(26) 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.(32)

### **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%)(21, 33) as was reported in a review by Romito et al. (34) However, having cancer, receiving treatment, and suffering from the side effects of treatment can have a tremendous effect on social bonding. (35) 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. (36) 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.

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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.(37) 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 time-period) never spoke about other ways of contact (e.g. telephone or online meetings) than face-to-face. Probably, other contacts are experienced as less impactful than face-to-face contact. During a COVID 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. Schellekens *et al* already reported the psycho-social burden of the pandemic on cancer patients, with additional fears and loneliness.(38) A report focusing on social distance problems among vulnerable groups in the Netherlands during COVID-times, showed – among other things – that COVID had a substantial impact on the elderly with 1 out of 7 experiencing loneliness and a substantial increase in mood and behaviour problems.(39) These findings with respect to friendship can help to better understand how friendship can stay alive during COVID-19, e.g. during tough times.(40)

### **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 well-being. In doing so, support provided by friends should be personalized 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.

### **Acknowledgments**

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### **Contributor statement**

HMB designed the study. ME carried out the study. ME, HMB, DdV, JS and GSS were involved in the interpretation of the study findings. ME and HMB wrote the manuscript which was critically read by all the authors. HMB 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.

### **Competing interests**

None

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### **Data sharing statement**

Apart from the data we presented in this paper, we have no additional data to share. However, the context surrounding specific quotes can be given, of course.

### **Ethics statement**

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3 An extensive ethical review was not deemed necessary by the hospital review committee (Antoni van  
4 Leeuwenhoek), and the ethical committee provided us with a declaration of no objection (P15CHR) after having  
5 seen the research protocol of the study. During the study we however asked for informed consent for every study-  
6 participant, and all data were analyzed anonymously.  
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For peer review only



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**Table 1. Definitions frequently used in the field of medical anthropology**

Definition	Interpretation
Friendship in sociology:	Friendships have been defined at the macro level (e.g., analyses of composition of friendship networks) and at the micro level (e.g., delineations of the features or characteristics of friendship relationships).  Friendship has also been conceptualized 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 organizations and systems through which support is mobilized 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 vs 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.

**Table 2. Friend characteristics<sup>1</sup>**

Patient	Friend	Gender	Relationship	Place / other
A (Sarah)	(1) Marion	F	Daughter in law <sup>2</sup>	Home
	(2) Alice	F	Friend	Home
	(3) Alana	F	Friend	Home
	(4) Megan	F	Ex-daughter in law <sup>2</sup>	Home
	(5) Hugo	M	Ex-husband <sup>2</sup>	Home
B (Jolene)	(6) Yvette	F	Sister <sup>2</sup>	Home
	(7) Elise	F	Friend	Home
	(8) Yasmine	F	Stepdaughter <sup>2</sup>	Home
C (Emma)	(9) Eva	F	Friend	Home
	(10) James	M	Partner <sup>2</sup>	Office
	(11) Helena	F	Friend	Office
D (Bob)	(12) Lennard	M	Friend	
E (Hestia)	(13) Livia	F	Friend	Home
	(14) Cecil	F	Partner <sup>2</sup>	Home

1. Names are pseudonyms to protect our informants.

2. 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.

## Coreq checklist

Friendship during the stable phase and instable phases of incurable cancer

### Domain 1: Research team and reflexivity

#### *Personal characteristics*

1. Interviewer/facilitator: Which author/s conducted the interview or focus group?  
**P3, in-depth interview approach.**
2. Credentials: What were the researcher's credentials? E.g. PhD, MD  
**P1**
3. Occupation: What was their occupation at the time of the study?  
**P1**
4. Gender: Was the researcher male or female?  
**P3, female**
5. Experience and training: What experience or training did the researcher have?  
**P3**

#### *Relationship with participants*

6. Relationship established: Was a relationship established prior to study commencement?  
**P3**
7. Participant knowledge of the interviewer: What did the participants know about the researcher? e.g. personal goals, reasons for doing the research?  
**P3**
8. Interviewer characteristics: What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic.  
**P3**

### Domain 2: Study design

#### *Theoretical framework*

9. Methodological orientation and Theory: What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis?  
**P3 (in-depth interviews, grounded theory)**

#### *Participant selection*

10. Sampling: How were participants selected? e.g. purposive, convenience, consecutive, snowball?  
**P3 Friends were approached via patients.**
11. Method of approach: How were participants approached? e.g. face-to-face, telephone, mail, email.  
**P3 (telephone/face-to-face; interviews)**
12. Sample size: How many participants were in the study?  
**P1 (abstract, 12 participants)**
13. Non-participation: How many people refused to participate or dropped out? Reasons?  
**P3 (none of the patients)**

#### *Setting*

14. Setting of data collection: Where was the data collected? e.g. home, clinic, workplace.  
**P3 (home/office)**
15. Presence of non-participants: Was anyone else present besides the participants and researchers?  
**P3 (no one else present)**
16. Description of sample: What are the important characteristics of the sample? e.g. demographic data, date  
**P4 (quantitative characteristics)**

*Data collection*

17. Interview guide: Were questions, prompts, guides provided by the authors? Was it pilot tested?  
**P3, the list was tested among several researchers and adapted during the follow-up of the interviews.**
18. Repeat interviews: Were repeat interviews carried out? If yes, how many?  
**No**
19. Audio/visual recording: Did the research use audio or visual recording to collect the data?  
**P5 (all conversations and interviews were audio-taped)**
20. Field notes: Were field notes made during and/or after the interview or focus group?  
**P4**
21. Duration: What was the duration of the interviews or focus group?  
**P3**
22. Data saturation: Was data saturation discussed?  
**P3, until data saturation was reached.**
23. Transcripts returned: Were transcripts returned to participants for comment and/or correction?  
**P3**

**Domain 3: Analysis and findings**

24. Number of data coders: How many data coders coded the data?  
**P3 (2, HMB, and MvE)**
25. Description of the coding tree: Did authors provide a description of the coding tree?  
**P3 (no explicit description of the coding tree, but we described several themes)**
26. Derivation of themes: Were themes identified in advance or derived from the data?  
**P3 (yes)**
27. Software: What software, if applicable, was used to manage the data?  
**P3**
28. Participant checking: Did participants provide feedback on the findings?  
No, but we sent them a lay version of the results.
- Reporting*
29. Quotations presented: Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number.  
**Yes, P4-6**
30. Data and findings consistent: Was there consistency between the data presented and the findings?  
**P4-6 (yes)**
31. Clarity of major themes: Were major themes clearly presented in the findings?  
**P4-6 (yes)**
32. Clarity of minor themes: Is there a description of diverse cases or discussion of minor themes?  
**P4-6 (yes)**

# BMJ Open

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

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

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## Running title

Friendship during stable and unstable phases of incurable cancer

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## Acknowledgments

The authors thank all patients and patients' friends who participated in this study. We further 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.

## Keywords:

COVID-19, ethics, health policy, internal medicine, medical ethics

## Word count

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**ABSTRACT**

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**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/friends' office.

**Results:**

Friends reported to experience difficulties in how and how often they wanted to approach their ill friends. They emphasized 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 patients' 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.

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**Strength and limitations**

- We did not provide any definition about friendship beforehand but let the patients choose who they considered to be friends (e.g. 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 from one single cancer hospital. Results may be different in another hospital where 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.
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## INTRODUCTION

The palliative phase of cancer can be considered an intense period for patients as well as close relatives.(1, 2) 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.(4) At present, the chronicity of 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 as a chronic illness.(5) Manderson and Smith-Morris (2010) for instance argue that “the use of the term *remission* rather than *cure* already draws attention to cancer’s chronicity”.(6) 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.(7)

Currently, the term ‘chronic’ in the context of incurable cancer receives increasing attention in the medical arena.(8) Dealing with those dilemmas in such an insecure disease phase appears to be a challenge for both the healthcare professional as well as the patient. (8, 9) Although the label chronic can be a relief for the patient, the differences across cancers bring along heated discussions among healthcare professionals. Patients have been shown to experience dilemmas, particularly because they are unsure about their prognosis, balancing in preparing themselves for their approaching death and having a desire to live their life such as before their diagnosis of cancer. (10) This disease phase therefore opens up new (unconscious and unmet) needs of patients and their close relatives in which social support, in the most broadest sense, could play an important role. The chronic nature of a disease brings along challenges for friends also, since the disease trajectory is less clear and therefore may impact their relationship. The long(er) time of a duration of a chronic disease, makes this topic more relevant for friendship compared to a short acute event. Furthermore, even without disease, longstanding friendship have different phases which may make it even more complex in case of chronic disease

Remarkably, limited literature about the socio-emotional adjustment of patients during this (protracted) disease phase of cancer exists. (11) 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. (12, 13) 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 cancer patients. (14) 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.(15) (14, 16) Kroenke *et al* (2006) for instance showed that socially isolated women had an elevated risk of mortality compared to socially integrated women after diagnosis of breast cancer. (17) Moreover, Taylor *et al* (1986) showed that individuals experiencing support from close friends tend to live longer and remain healthier including a more positive outlook when faced with adversity. (18)

The definition of friendship varies across disciplines but often accompanies the following elements: Trust, communication and intimacy. (19) Both family members as well as non-family members can be considered as friends, and an overarching quote such as ‘I would rather walk with a friend in the dark, than alone in the light (Hellen Keller)’ explicates the import role friendships can have. Close relatives and family members may already have a natural bond with the patient but do 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 on cancer patients’ quality of life important. While the role of family members as informal caregivers has been acknowledged in the literature (20, 21), 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, 22) Given the lack of literature about the role of friendships, the potential important role of friends in supporting people with advanced cancer – this 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.



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## 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. (8, 23) 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 (24) (inductively) and analyzed with a thematic approach (deductively). Data analysis started (almost) simultaneously with data collection, which continued to inform each other throughout the research process.(25) This gave the process of data-collection an iterative-inductive character.

In doing this, we verified the hypothesis as to whether friends supported their ill friends without viewing this as too burdensome for themselves. Thematic analysis was done by exploring the data with an open-minded approach, having no preconceived ideas beforehand in what would be 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. That's why we chose for this open 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 to 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.(26)

Friends can, during chronic disease, be 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 (ADLs) or instrumental activities of daily living (IADLs) 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.(27) Friends may demonstrate immense faithfulness, dependability or responsibility toward 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, e.g. this background information helped us in the formation of themes to understand how friendships were shaped in this sample.

[Table 1 about here]

### Data collection

This study was performed in a Comprehensive Cancer Centre in the Netherlands. In the period February 2018 – May 2018 fourteen 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 (a Dutch comprehensive cancer centre). Since patients (previously being interviewed about their disease experiences (8)) were the starting-point of data collection, all friends we recruited were linked to patients in one specific hospital. All patients were middle-aged, e.g., between 40-70 years old, 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).

[Table 2 about here]

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3 The interviews were semi-structured. By using a topic list, MvE tried to mention several topics (sometimes illustrated  
4 with detailed example sentences) in every interview. This topic list was pretested with HMB. She always somewhere  
5 during the interview asked the general question: "What does cancer mean to you?" to get a little more grip in how  
6 patients experienced their disease.<sup>1</sup> Moreover, questions about how friends got to know their ill friend, previous  
7 personal experiences with cancer, issues that were considered particularly challenging, the frequency of visits to  
8 their friends, difficulties they experienced with their friends, whether they at a certain moment felt they were a  
9 caregiver (e.g. someone who need to take care of someone, instead of being a friend only) (In Dutch: *mantelzorger*),  
10 whether they experienced any rituals together with their friend, et cetera.

### 11 **Data Analysis**

12 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  
13 HMB, a female researcher in the field of palliative care and oncology, to analyse the data herself. Nine interviews  
14 were discussed twice at different time intervals to seek for themes (MvE, HMB). These themes were discussed to  
15 check for interpreter consensus. Subsequently, a scheme was developed to index text fragments with similar  
16 content. Simultaneously, by analysing the data, principles of grounded theory were used, e.g. data analysis started  
17 (almost) simultaneously with data collection, which continued to inform each other throughout the research  
18 process.<sup>(24)</sup> The process of data-collection accordingly resulted in an iterative-inductive character.<sup>(25)</sup> Initial data  
19 was analyzed to look for emerging themes, which in turn informed the content of upcoming interviews. It means  
20 that analysing the data thematically, and using grounded theory went hand in hand. The discovery of theory from  
21 data (e.g. grounded theory) is a major task confronting sociology, for such a theory fits empirical situations, and is  
22 understandable to sociologists and laymen alike. During the analysis, all hypotheses that we formulated were  
23 checked with the data (HMB and ME). Interviews were stopped after data saturation was reached. This is the  
24 moment no new information are mentioned by the participants (friends) in relation to the research questions as  
25 have been posed in the introduction section.

26 We all evaluated whether the final quotes were used in the right context. Transcripts were not returned to the friends.  
27 All transcripts were audio-recorded and transcribed; All of the names are pseudonyms; Several items to ensure  
28 adequate qualitative research were checked with the COREQ-checklist, which is of course not a guarantee of the  
29 quality of the research itself. <sup>(28)</sup>

### 30 **Ethics**

31 An extensive ethical review was not deemed necessary by the hospital review committee (Antoni van  
32 Leeuwenhoek), and the ethical committee provided us with a declaration of no objection (P15CHR) after having  
33 seen the research protocol of the study. During the study we however asked for informed consent for every study-  
34 participant, and all data were analyzed anonymously.

### 35 **Public and patient involvement**

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

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## 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. Nevertheless, friends reported that uncertainty to a certain extent always existed, and they therefore sometimes used the word 'Sword of Damocles' to describe the feeling during the course of their friends' disease.

*[...] 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? Yvette [Patient B, participant 6, family-related friend]*

Friends for whom this was their first experience with cancer or who had no prior experience with health care, 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... Megan (Patient A, participant 4, family-related friend)*

During all interviews it became clear that the experiences friends had 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, at the same time, they 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. [...] Look, cancer has influence on me in the way that it makes me aware of my blessings. Alice (Patient A, participant 2, 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. With her [Hestia] there hangs this... even though sometimes I forget, but I am occasionally reminded of it. Livia (Patient E, participant 13, 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 friend, the patient, 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 realized they were more ill than expected.

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

*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. And so this one time, we went away for the weekend, and then you realize: Gee, she walks a bit strange and her balance is off [...] and then you realize: Jesus she is in worse shape than I thought." Yasmine*

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 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'. The prolonged time span sometimes resulted in situations where being sick and the 'sick role' escaped the consciousness of the social network.

Both emotions: Guilt and powerlessness as well as manifestations of gratitude and appreciation were shown by the friends. Sometimes, friends stated that they would feel 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 topic 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 [of other people with cancer] with her just for the sake of her having the same condition... and imagine everyone sharing their stories on other 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. But yeah, I do think that I make certain choices because of it, although I don't consider that to be a bad thing. Otherwise I would not do it like that haha.*

## Support

All friends reported to try to give some 'personal' form of support. However, support was demonstrated in different manners, albeit 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. Alana (Patient A, participant 3, 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 personalized, 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. Megan (Patient A, participant 4, 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

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

10  
11 *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*  
12 *feel it. [...] She lives alone. And it also comes from a basic instinct, or feeling, that we have had for each other.*

13 *I: Also a sense of responsibility?*

14 *R: No, a sense of responsibility feels too strong for me. I am not responsible for either*  
15 *her or her situation. But I want to stand by her and help her in this situation.*

16 *Hugo (Patient A, participant 5, family-related friend)*

17  
18 This contrasted with what some other more direct family members experienced. Since, when there is a partner,  
19 they would naturally take over a considerable part of the care demand. Some of the friends felt burdened with or  
20 forced in providing more care than they were willing to provide. Nevertheless, friends also indicated that there might  
21 be circumstances to step in more than they were initially willing to at some point. They acknowledged that there is  
22 always a possibility of support translating into care when circumstances demand such a shift. However, friends  
23 noted that it is in this *possibility* that lies the tricky part for friends – that is to say, they actively seemed to negotiate  
24 the extent of their support, and tried to find balance in what they can give, what they themselves received, and what  
25 they need to reserve for other relationships in their lives.

26  
27 *You know, the way you go about these things really depends on the person across from you, and subsequently*  
28 *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*  
29 *to have some energy left. Alana (Patient A, participant 3, 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 cancer patients, 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.

### Remarkable 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.(26) 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.(30)

### 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%)(21, 31) as was reported in a review by Romito et al. (32) However, having cancer, receiving treatment, and suffering from the side effects of treatment can have a tremendous effect on social bonding. (33) 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. (34) 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 time-period) never spoke about other ways of contact (e.g. telephone or online meetings) than face-to-face. Probably, other contacts are experienced as less impactful than face-to-face contact. During a COVID 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. Schellekens *et al* already reported the psycho-social burden of the pandemic on cancer patients, with additional fears and loneliness.(36) A report focusing on social distance problems among vulnerable groups in the Netherlands during COVID-times, showed – among other things – that COVID had a substantial impact on the elderly with 1 out of 7 experiencing loneliness and a substantial increase in mood and behaviour problems.(37) These findings with respect to friendship can help to better understand how friendship can stay alive during COVID-19, e.g. during tough times.(38)

### 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

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3 were surprised to be approached as a friend. It however could also mean that patients lost some friends outside a  
4 family context and accordingly mentioned more family members as friends. Another feature is that we often  
5 interviewed more than one friend/family member surrounding an ill friend, which enabled us to make comparisons  
6 and put the qualitative data in context. Although we did not include this information explicitly (anonymity), this  
7 increased our understanding substantially.

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

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

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

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

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

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

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51 Schildmann for his comments on a previous version of this manuscript.

### 52 **Contributor statement**

53 HMB designed the study. ME carried out the study. ME, HMB, DdV and GSS were involved in the interpretation of  
54 the study findings. ME and HMB wrote the manuscript which was critically read by all the authors. HMB is guarantor  
55 of the study. All authors had full access to all the data in the study and can take responsibility for their integrity and  
56 the accuracy of their analysis.

### 57 **Competing interests**

58 None  
59  
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4 **Funding**

5 Ars Donandi  
6 Janssen

7  
8 **Data sharing statement**

9 Apart from the data we presented in this paper, we have no additional data to share. However, the context  
10 surrounding specific quotes can be given, of course.

11 **Ethics statement**

12 An extensive ethical review was not deemed necessary by the hospital review committee (Antoni van  
13 Leeuwenhoek), and the ethical committee provided us with a declaration of no objection (P15CHR) after having  
14 seen the research protocol of the study. During the study we however asked for informed consent for every study-  
15 participant, and all data were analyzed anonymously.  
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For peer review only



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**Table 1. Definitions frequently used in the field of medical anthropology**

Definition	Interpretation
Friendship in sociology:	Friendships have been defined at the macro level (e.g., analyses of composition of friendship networks) and at the micro level (e.g., delineations of the features or characteristics of friendship relationships).  Friendship has also been conceptualized 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 organizations and systems through which support is mobilized 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 vs 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.

**Table 2. Friend characteristics<sup>1</sup>**

Patient	Friend	Gender	Relationship	Place / other
A (Sarah)	(1) Marion	F	Daughter in law <sup>2</sup>	Home
	(2) Alice	F	Friend	Home
	(3) Alana	F	Friend	Home
	(4) Megan	F	Ex-daughter in law <sup>2</sup>	Home
	(5) Hugo	M	Ex-husband <sup>2</sup>	Home
B (Jolene)	(6) Yvette	F	Sister <sup>2</sup>	Home
	(7) Elise	F	Friend	Home
	(8) Yasmine	F	Stepdaughter <sup>2</sup>	Home
C (Emma)	(9) Eva	F	Friend	Home
	(10) James	M	Partner <sup>2</sup>	Office
	(11) Helena	F	Friend	Office
D (Bob)	(12) Lennard	M	Friend	
E (Hestia)	(13) Livia	F	Friend	Home
	(14) Cecil	F	Partner <sup>2</sup>	Home

1. Names are pseudonyms to protect our informants.

2. 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.

## Coreq checklist

Friendship during the stable phase and instable phases of incurable cancer

### Domain 1: Research team and reflexivity

#### *Personal characteristics*

1. Interviewer/facilitator: Which author/s conducted the interview or focus group?  
**P3, in-depth interview approach.**
2. Credentials: What were the researcher's credentials? E.g. PhD, MD  
**P1**
3. Occupation: What was their occupation at the time of the study?  
**P1**
4. Gender: Was the researcher male or female?  
**P3, female**
5. Experience and training: What experience or training did the researcher have?  
**P3**

#### *Relationship with participants*

6. Relationship established: Was a relationship established prior to study commencement?  
**P3**
7. Participant knowledge of the interviewer: What did the participants know about the researcher? e.g. personal goals, reasons for doing the research?  
**P3**
8. Interviewer characteristics: What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic.  
**P3**

### Domain 2: Study design

#### *Theoretical framework*

9. Methodological orientation and Theory: What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis?  
**P3 (in-depth interviews, grounded theory)**

#### *Participant selection*

10. Sampling: How were participants selected? e.g. purposive, convenience, consecutive, snowball?  
**P3 Friends were approached via patients.**
11. Method of approach: How were participants approached? e.g. face-to-face, telephone, mail, email.  
**P3 (telephone/face-to-face; interviews)**
12. Sample size: How many participants were in the study?  
**P1 (abstract, 12 participants)**
13. Non-participation: How many people refused to participate or dropped out? Reasons?  
**P3 (none of the patients)**

#### *Setting*

14. Setting of data collection: Where was the data collected? e.g. home, clinic, workplace.  
**P3 (home/office)**
15. Presence of non-participants: Was anyone else present besides the participants and researchers?  
**P3 (no one else present)**
16. Description of sample: What are the important characteristics of the sample? e.g. demographic data, date  
**P4 (quantitative characteristics)**

*Data collection*

17. Interview guide: Were questions, prompts, guides provided by the authors? Was it pilot tested?  
**P3, the list was tested among several researchers and adapted during the follow-up of the interviews.**
18. Repeat interviews: Were repeat interviews carried out? If yes, how many?  
**No**
19. Audio/visual recording: Did the research use audio or visual recording to collect the data?  
**P5 (all conversations and interviews were audio-taped)**
20. Field notes: Were field notes made during and/or after the interview or focus group?  
**P4**
21. Duration: What was the duration of the interviews or focus group?  
**P3**
22. Data saturation: Was data saturation discussed?  
**P3, until data saturation was reached.**
23. Transcripts returned: Were transcripts returned to participants for comment and/or correction?  
**P3**

**Domain 3: Analysis and findings**

24. Number of data coders: How many data coders coded the data?  
**P3 (2, HMB, and MvE)**
25. Description of the coding tree: Did authors provide a description of the coding tree?  
**P3 (no explicit description of the coding tree, but we described several themes)**
26. Derivation of themes: Were themes identified in advance or derived from the data?  
**P3 (yes)**
27. Software: What software, if applicable, was used to manage the data?  
**P3**
28. Participant checking: Did participants provide feedback on the findings?  
No, but we sent them a lay version of the results.
- Reporting*
29. Quotations presented: Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number.  
**Yes, P4-6**
30. Data and findings consistent: Was there consistency between the data presented and the findings?  
**P4-6 (yes)**
31. Clarity of major themes: Were major themes clearly presented in the findings?  
**P4-6 (yes)**
32. Clarity of minor themes: Is there a description of diverse cases or discussion of minor themes?  
**P4-6 (yes)**

## *Expression of concern: Friendship during patients' stable and unstable phases of incurable cancer: a qualitative interview study*

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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/bmjopen-2021-058801.

This is a note of a temporary expression of concern related to the above-mentioned publication.

BMJ has received notification from Professor Gabe Sonke, disputing the accuracy of this article. Professor Sonke has stated that he did not write, review, or participate in any way with the production and submission of this manuscript.

The authors were asked to resolve this dispute, however they have failed to come to an agreement. BMJ is not in a position to adjudicate authorship disputes. In line with guidance issued by the Committee on Publication Ethics (COPE), BMJ has decided not to alter the article itself in this instance and has informed the authors' affiliated institutions listed on the article of the dispute.

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