European Journal of Oncology Nursing 38 (2019) 98–103

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Cancer patients' experiences of communicating and dealing with their older parents: A qualitative study

Liesbeth Van Humbeeck[a,*], Let Dillen[a], Ruth Piers[a], Mieke Grypdonck[b], Sofie Verhaeghe[b], Nele Van Den Noortgate[a]

[a] *Department of Geriatric Medicine, Ghent University Hospital, Ghent, Belgium*
[b] *University Centre for Nursing and Midwifery, Department of Public Health and Primary Care, Ghent University, Ghent, Belgium*

ARTICLE INFO

Keywords:
Interaction
Older parent
Patient
Qualitative study
Cancer
Relationship
Process
Communication
Experiences

ABSTRACT

Purpose: In 2017 almost 25,000 Belgians between 40 and 60 years (38% of new diagnoses) were diagnosed with cancer. With increasing life expectancy the chance augments that these patients still have older parents alive. This implies that oncology care should also take into account the impact cancer may have on (the relationship with) older parents. The purpose of this study was to explore how cancer patients communicate and deal with their older parents during the illness trajectory.

Method: Semi-structured interviews were conducted with 11 cancer patients. Interview transcripts were analysed using the principles of the constructivist Grounded Theory Approach.

Results: Depending on the situation, the time frame and the person the patients are talking about, cancer patients oscillate between perspectives (I, They and We). A common denominator in all three perspectives is silence fuelled by different forms of solicitude (self-protection and other-protection). This solicitude underpins the cancer patients' communicative behaviours and ways of relating towards their parents.

Conclusions: Present findings underline the importance of health care providers considering the often hidden complexity of giving information and talking about feelings. Nurses' strategies must be designed not to harm the existing mechanism of solicitude and the diligent management of the patients' relationship with their parents. Conversations about functionality of avoiding certain topics and the impetus behind certain communicative patterns should be put forward instead of consensually advising open communication.

1. Introduction

Cancer is a major cause of morbidity and mortality, with approximately 14 million new cases and 8 million cancer-related deaths in 2013, affecting populations in all countries and all regions. In 2017 almost 25,000 Belgians (38% of new diagnoses) between 40 and 60 years old were diagnosed with cancer (Belgian Cancer Registry, 2018).

With the shift of contemporary cancer treatment from hospital settings to outpatient settings the burden of care has moved from health care providers to patients and their family caregivers (Northouse et al., 2012). Family members provide the context for this experience, and are often profoundly affected by the disease (Caruso et al., 2017; Kershaw et al., 2015; Kim et al., 2016). Whilst there is a range of research which identifies the importance of meeting family needs, few studies explore the older parent-child relationship in case of the child having cancer (Van Humbeeck et al., 2013). Prior research on impact of cancer diagnosis has tended to shed light on parent-young child dyads (Sulkers et al., 2015) and the couple relationship (Hendriksen et al., 2015; Senden et al., 2015). Even when having parents until late adulthood has almost become a ‘normal’ life situation, and compared to earlier times, the shared life span of parents and adult children is extended to almost six decades (Levitzki, 2009). In case of a cancer diagnosis this may bring about new roles, expectations, sources of support and also sources of conflict and strain (Askham et al., 2007).

Several studies emphasize the linked lives of parents and middle-aged children and reveal multiple ways in which relationships with children remain an important influence on parental wellbeing throughout the life course (Fingerman et al., 2012; Ward, 2008). Current research either centres on older parents having a child with a mental illness, psychiatric condition or developmental disability (Copeland and Heilemann, 2011; Johansson et al., 2015) or it analyses the adult child's perspective of having an older parent with cancer (Fisher et al., 2017; Kim et al., 2008; Pryce et al., 2017; Raveis and Pretter, 2005). To date, insight in the adult cancer patient's perspective

---

[*] Corresponding author. Ghent University Hospital, Department of Geriatric Medicine, Corneel Heymanslaan 10, 9000 Ghent, Belgium.
E-mail address: liesbeth.vanhumbeeck@uzgent.be (L. Van Humbeeck).

https://doi.org/10.1016/j.ejon.2018.12.005
Received 21 February 2018; Received in revised form 13 December 2018; Accepted 16 December 2018

on this relationship after a cancer diagnosis is virtually non-existent (Fisher, 2010). Therefore, this study investigated how adult cancer patients communicate and deal with their older parents during the illness trajectory.

2. Methods

2.1. Study design

This study was designed as an explanatory qualitative study with an inductive approach including interviews (Gubrium et al., 2012).

2.2. Setting and sampling

The study was conducted at the Ghent University Hospital. We used purposive sampling to gain rich information from a range of perspectives. Cancer patients eligible for participation were: (1) between 30 and 60 years old, (2) under active treatment or post-therapy surveillance, (3) with at least one parent being alive, (4) able to provide informed consent and complete an interview, and (5) Dutch native speakers. Patients were approached by a trusted health care provider (HCP). Only when permission was given, contact information was passed on to the researcher. Interviews were either conducted at the patient's home or the hospital, as preferred by the patient. This qualitative study was part of a larger project designed to examine the relationship dynamics between cancer patients and their older parents. Only the results of the adult child's experience vis-à-vis his older parent (s) are presented here. The findings concerning the parents' experiences are reported elsewhere (Van Humbeeck et al., 2015).

2.3. Data collection

One-time semi-structured interviews with an open character were conducted by a female researcher (L.D). The interviewer had no previous relationship with the participants. The interviewer (L.D), a clinical psychologist and researcher, was trained and coached by two experienced qualitative researchers (L.V.H and M.G). The interviews began with exploratory questions about the person's illness trajectory and his relationship with his parents. Subsequently, more in-depth questions were asked to collect data on their position as a sick child with regard to their parents and on the perception of changes in the interaction with their parent(s) during the illness trajectory, in the communication with their parent(s), and in the support given by their parent(s) and significant others, and their position as a sick child with regard to their parents. The interview guide (Table 1.) was refined progressively throughout analysis.

2.4. Data analysis

Analysis was based on the principles of the constructivist Grounded Theory Approach (Charmaz, 2014). This method enables the exploration of conceptual themes and underlying mechanisms at play. We brought to the fore several elements that characterize a grounded theory study: theoretical sensitivity, theoretical sampling, constant comparative methods, coding and memoing. First, interviews were read entirely to obtain an overall picture of the interview. Subsequently, each interview was coded by L.V.H. and L.D. An entirely inductive approach to coding was employed without any pregiven coding scheme. Coding discrepancies were reconciled through discussion between the two main coders (L.V.H. and L.D.) and within the research team. By comparing interviews and coded fragments, concepts were developed that guided the next wave of data collection. Finally, the emerging concepts, categories, and relationships between categories were clarified by carrying out new interviews, and reanalysing previous interviews. The interpretative process of analysis was underpinned by reflexivity, ensuring openness to the meaning of the data and a general tenet to question, criticize and explicate understandings of the data (Malterud, 2001). Data analysis was supported by the software program NVivo10 (QSR International).

Table 1
Example questions from the interview guide.

With whom did you talk about your cancer diagnosis ?
What did you talk about ? What makes that you wanted to talk with these people about these topics ? Which topics are discussed with your parents ? How do you deal with your parents during the illness trajectory ? To what extent has your relationship with your parents changed since diagnosis ? In what way did it change ?

2.5. Rigor and trustworthiness

Several strategies were used to ensure trustworthiness of our results (Lincoln and Guba, 1985). Each interview was audio taped, transcribed verbatim and verified for transcription accuracy. Validity of data collection was enhanced by peer review of the interview style. Memos were written on the interview context and interpretations of themes. To enhance the validity of the interpretations, multidisciplinary researcher triangulation was used in all phases of the study.

All authors regularly discussed the emerging themes and their personal reactions to the material. Preliminary findings were presented and reflected on during meetings of nurses, psychologists, social workers of the Oncology Centre at the Ghent University Hospital. To enhance dependability the research and interpretation process was written down by means of an audit trail.

2.6. Ethical considerations

The study protocol was approved by the Ethics Committee of the Ghent University Hospital (B670201112271). All participants were given written and verbal information about the study and gave informed consent to participate. All data have been anonymized. The COREQ checklist guided the preparation of this manuscript (Tong et al., 2007).

3. Results

3.1. Participants

Interviews were conducted with 11 adult cancer patients between 33 and 58 years old. With the exception of one man, participants were all women. They were in various stages of cancer resulting in different treatments regimens. There was a predominance of breast cancer patients. Interviews took place between February 2013 and May 2015, and lasted on average 74 min (ranging from 36 to 152 min). Participants' characteristics are listed in Table 2.

3.2. Parents as not self-evident in the stories of the adult cancer patients

As participants described how they dealt with and communicated about their illness, it became evident that their parents didn't play a leading part in their stories (especially when being married). In most interviews the large family connections came to the plane whilst the older parents mostly were figurants at the margin. Cancer patients, who had a partner and (dependent) children, often turned to their nuclear family for support, communication, and concern. In these instances the older parents constituted the secondary circle of support and concern. The findings described in this article thus pertain to older parents and the wider environment of a middle-aged cancer patient. Below we will set out the key categories emerging from the cancer patients'

Table 2
Sociodemographic and illness-related characteristics of participants (N = 11).

Sociodemographic Characteristics		
Gender, N (%)		
Male	1	(9)
Female	10	(91)
Age (years), N (%)		
< 40	2	(18)
40–50	4	(36)
51–60	5	(46)
M; range	48.5	33–58
Marital Status, N (%)		
Married or living together	8	(73)
Partnership, not living together	1	(9)
Single	2	(18)
Number of children		
0	1	(9)
1	2	(18)
2	3	(27)
3	4	(36)
4	1	(9)
Age (years) of children *M*; range	20.2	4–33
Contact with parents, N (%)		
Daily	6	(55)
Weekly	3	(27)
Monthly	1	(9)
According to necessity	1	(9)
Parents alive, N (%)		
Only mother alive	4	(36)
Only father alive	1	(9)
Both parents alive	6	(55)
Marital status of parents, N (%)		
Widowed	4	(36)
Married	7	(64)
Living situation parents, N (%)		
Independent	10	(91)
Nursing home	1	(9)
Illness-Related Characteristics		
Type of cancer, N (%)		
Breast cancer	9	(82)
Bowel cancer	1	(9)
Hematological disease	1	(9)
First-time diagnosis or recurrence, N (%)		
First-time diagnosis	7	(64)
Recurrence	4	(36)

interviews. Although each category will be discussed separately and in a linear fashion, they are interwoven in multiple and complex ways. The illustrative quotes have been slightly edited for reading ease.

3.3. A phenomenon of silence

Participants all reported making decisions about how to communicate about their cancer. Three perspectives (I, They and We) emerged with regard to how patients relate to their family members, and their older parents in particular. A common denominator in the three perspectives is silence. This silence can be accounted for by the solicitude underpinning it. Below we will set out these three perspectives, the ensuing silence and the undercurrent of solicitude.

3.3.1. Three perspectives (I, They and We)

These 3 perspectives constitute easily observable behaviour and communication of cancer patients. Fig. 1 shows the three perspectives complemented with some main considerations (frames with dashed lines) grounding the pendulum between perspectives. The main characteristics of these perspectives are discussed below.

The I-perspective The *I*-perspective originates from a patient's quest for recognition of his everyday struggle with cancer. Participants experienced disappointment, abandonment and anger when their environment's reactions were perceived as insensitive, uncaring or unhelpful. Often participants felt silenced by others who either dismissed or trivialized their diagnosis or feeling state. Participants acknowledged that some people were unable to cope with the implications of cancer. They avoided contact with these people in an attempt to reduce their own distress. To cope with these social interactions, strategies included carrying on as usual, but also censoring conversations when necessary. These participants showed a peripheral way of empathy as the ability of others to cope was not the focus of their attention. Participants became highly self-absorbed by means of turning inwards, disengaging from their environment, and shutting down emotionally. This protective withdrawal is prompted by an urge of self-care and self-protection. As these patients didn't want to cope with other people's distress in addition to their own they tuned out and adopted an, at first sight, emotionally stoic attitude.

> It's me who has got the illness and they can't cope. (…) It's quite a burden to have to be responsible for other people's emotions.(…)To be honest I didn't have the energy or the wherewithal to be able to tell any of my friends; and I didn't want to have to deal with their feelings or face any repercussions. I could only focus on my husband and children. (Interview 10, 44-years old female breast cancer patient, married).

> In retrospect I talked about my behaviour with my parents. I asked them to see it from my perspective. Because in the end they just watch it happen. I and only I needed to deal with it on a daily basis. So it's also my decision when and how I talk about my diagnosis or feelings. (Interview 1, 56-years old female breast cancer patient, married).

The They-perspective In the *They*-perspective the overall tendency of the patient is to protect the environment, in particular the older parents. This mind-set is typified by a noticeable lack of emotional expression and a withholding of information, leaving both parties suffering in silence. Participants report wanting to disclose information in the best possible way without off-loading emotionally onto others. Even though participants were sure their parents knew how scared they were and how much they worried, they never gave voice to these feelings to avoid hurting or upsetting their parents.

> I just try to stay upbeat about it and that gives them (parents) hope and encouragement, so everybody can stay on the positive side. (…) It's really hard for me to stay upbeat. Occasionally it happened that I was crying during the car ride to my parents, but when I entered their house I carried on during that short period of time. So yeah I'm very cautious and wary in sharing information or displaying emotions to others. I don't tell them everything about all my emotional states. (Interview 11, 49-years old breast cancer patient, married).

> I have difficulty in seeing the sadness in their eyes. I can't stand that. It's really hard because when I'm down I feel that might bring them down too. It comes down to a feeling of guilt. I often feel guilty because I cause so much distress and sorrow. And I can't bear that. I just can't. (…) They've got enough to cope with. The bottom line is that you keep silent, become more guarded just in order to shield the others. To be considerate. (…) You just really try to shield them (parents) from bad things that are happening … there's sometimes no need to tell them. (Interview 1, 56-years old breast cancer patient, married).

Certain aspects, like the possibility of recurrence and the fear about death, were less likely to be a topic of conversation because of a sense of protectiveness. These participants strove to give a compromised version of the truth and conveyed a positive and hopeful perspective by “acting normal”. Participants strategize about how to deliver the news of their diagnosis to family members and the broader social network.

The We-perspective The *We*-perspective is characterized by a high sense of closeness, mutuality, and a willingness of both actors to communicate about difficult topics with a sense of humour. Some participants appraised cancer as a joint stressor which they ‘fought’ together.

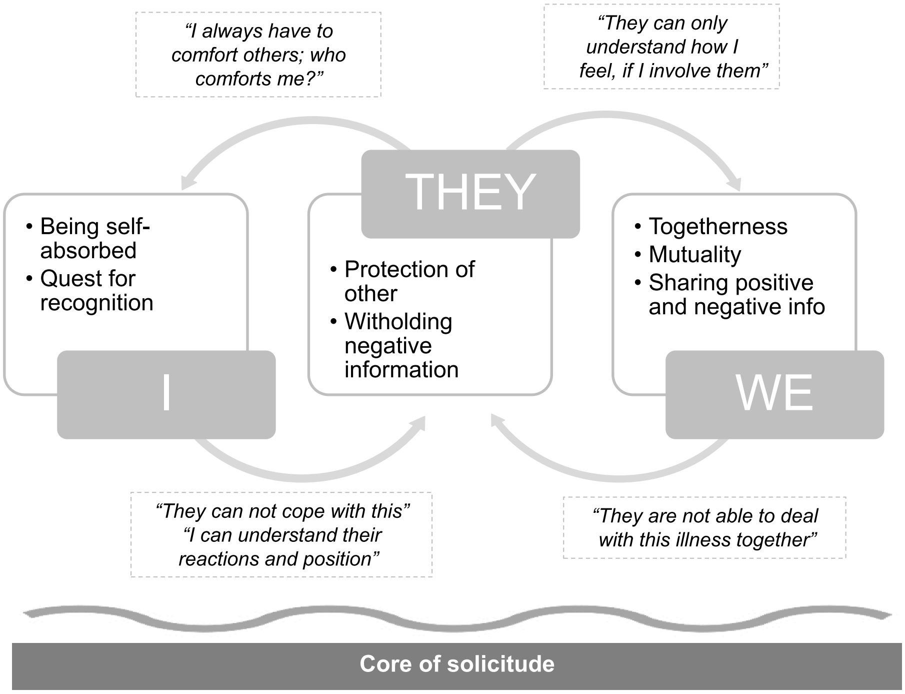

Fig. 1. Fluctuations between "We", 'I" and "They" throughout the cancer experience: Shifts in focus and priorities.

Participants talked about a "tell it all" style of communication marked by being open in discussing the experience without any attempts to hold back difficult information. Despite that these participants adamantly state that they could be honest and open about feelings and needs, they recount several instances in which they or other family members avoided topics. These accounts seem to contradict the claim of consistent, total and unequivocal openness.

> I feel very much that we are in this together, I feel that this is a crisis … or passage that we need to go through together. We've got a kind of sense that whatever, whatever happens that, you know, we'll be able to get through it, manage it, make it as good as we can. And we cry with each other when things seem hopeless. That is certainly possible, but not too much. We will not burden each other. And she (mother) will not always share the things that weigh on her mind and me neither. (Interview 9, 33 years old breast cancer patient, married).

With *I, We and They* as anchors, the narratives showcase the possibility of switches between the 3 perspectives. We briefly describe considerations underlying these perspective switches (Fig. 1., dashed lines).

- A shift from the I-perspective to the They-perspective was often motivated by a certain clemency for the reactions of others. Previous comments or ways of relating that were first regarded as a lack of respect or recognition of their illness were now considered as evidence of an inability of the other to cope with the cancer (diagnosis).

  And yeah she (mother) avoided me. And she never asked directly how I was doing, but always through the grapevine. Through my sister or brother. I blamed her for a lack of interest in my situation. After a while, and after several conversations with a psychologist I could put things in perspective. She presumably couldn't handle the situation. She denied it to herself and, you know, I distanced myself on purpose. (…) Eventually, I made efforts to come closer together as I realized that she didn't want to burden me with questions. (Interview 1, 56-years old breast cancer patient, married).

- A shift from a They-perspective to a We-perspective stems from a consideration that not involving the other is unfair because it deprives the other the opportunity to cope with the cancer diagnosis. Not disclosing felt like lying and being dishonest. This switch can also be indicated by the belief that the other can only offer support if they aren't shut out of the experience.

  I originally tried to keep my distress private from friends and family to not worry them, but I soon found this unhelpful and subsequently shared with them. (Interview 2, 58 years old breast cancer patient, married).

- A shift from a They-perspective to an I-perspective arose in patients who met with stigmatizing responses of people they first tried to protect. This entailed a preference to be uncommunicative and detached.

  And you sort of think, where am I in all this? And so all of a sudden it was enough. In the end it's me who's got the illness, who needs to survive and clearly my brother can't cope with it. He gave such hurtful comments. Practically denying my cancer diagnosis. In the beginning I tried to understand his reaction. I really love him, but he just drifted away. (Interview 5, 50-years old breast cancer patient, married).

- A shift from a We-perspective to a They-perspective was most noticeably seen in cases of poor prognosis and a transition to palliative care. This distancing and withholding emerged from the concern of burdening their already stressed family members.

  Then they said it was terminal. They can't help me anymore. The oncologist proposed an experimental chemotherapy regimen. But I said no to that. (…) This I can't share with her … this bad news I can't tell this to my mother. We share our joys and sorrows and I live with her since a couple of years. Normally I should take care of her and instead she is taking care of me while being in such poor health. I'm now preparing my funeral with my son, but I can't involve my mother in these arrangements. (Interview 6, 58-years old breast cancer patient, divorced).

A certain solicitude lies hidden "underneath" all three perspectives.

This solicitude forms the underlying process that drives participants to display certain communicative behaviours and ways of relating towards their parents (and wider environment).

3.3.2. A core of solicitude

The avoidant communicative strategies characteristic for the three aforementioned perspectives resulted in silence. However, this silence was fuelled by different forms of solicitude (e.g. to preserve the self or the other). An undercurrent of solicitude with regard to oneself (self-protection) at one end and solicitude with regard to others (other-protection) at the other end was prevalent (Fig. 1). This was not openly discussed and not so obvious. A unilateral focus on self-protection often stemmed from the anticipation that talking to others could evoke fear and distress in other people and oneself. Participants were also driven by other-protection motivations when they contained the impact of the illness for others in order not to overburden them.

4. Discussion

Overall, our findings give insight in how interaction may unfold between a cancer patient and his older parent(s), and what the seed-bed is for this communicative behaviour. A significant finding is that parents were not self-evident in the stories of adult cancer patients, especially when they were married. One explanation for this is that marriage in itself sets in motion a culturally rooted tendency to emphasize the independence and integrity of this nuclear family. In the hierarchy of obligations (Ungerson, 1987), the partner is primary carer and parents in that instance constitute the secondary carers. Another explanation may be that having a partner generates “exclusive family intimacies” pushing other intimates such as parents further away (Ketokivi, 2012; Rozer et al., 2016).

Participants struggled with how to talk or not to talk about the diagnosis, treatment and related concerns. Our findings reinforce previous studies that point out that cancer patients engaged in intricate communication work (Donovan-Kicken et al., 2012; Selman et al., 2015)’. Within many interviews, patients were the central gatekeeper of information, and their wishes regarding what should be discussed influenced communication with their parents. Openness and avoidance as salient aspects of the cancer experience were previously described in couples' cancer-related communication (Miller, 2014) and our findings confirm that this also applies to the older parent-adult child dyad. Present findings are in line with the communication privacy management theory (Petronio, 2002) which posits that individuals purposely select what information to share or withhold from others and as such claim ownership of their information. Telling involves many emotions that challenge participants' sense of control and which, in turn, they attempt to control both directly and through the way they communicate. Our findings clearly underpin the construction of boundaries relating to who is privy to certain information. Similarly, employing selectivity regarding topics and depth of talk was common in HIV patients (Edwards et al., 2014) and couples dealing with a cardiac event (Goldsmith and Miller, 2014).

Current study found that the cancer patients' self-silencing, as a feature of each of the three perspectives, could stem from other- or self-protection and was either self-inflicted or other-inflicted. Other research (Brandes et al., 2016; Manne et al., 2014) has shown that cancer patients' emotional attitudes (internal barrier) and perceived social norm (external barrier) were the most important determinants of their intention to express concerns. In several studies, patients have reported feelings of sorrow when witnessing the pain of loved ones, guilt for causing this upset, and worry that disclosure may result in emotional anguish for family members (Hilton et al., 2009; Manne et al., 2007; Yoo et al., 2010). To this extent, our participants' accounts are consistent with the broader literature, suggesting that different thought processes (e.g. avoidance of psychological distress, desire for mutual protection against harmful situations, and belief in positive thinking) may contribute to a phenomenon of silence (Edvardsson and Ahlstrom, 2008; Zhang and Siminoff, 2003). However, a previous study showed that the well-intended hiding of emotional reactions for their parents may in fact create the opposite of what these cancer patients are trying to achieve (Van Humbeeck et al., 2015).

5. Clinical implications

Present findings have implications for the (psychological) care of cancer patients. First, our findings underline the importance of looking beyond overt behaviour and to be aware of the caring solicitude that can ground this behaviour. Acknowledging the underlying mechanism of solicitude (other-protection and self-protection) during family conferences can make a big difference in how family and patient can interact with each other and with nurses. Second, many nurses advice families managing cancer to engage in open, direct communication, expressing needs and emotions. Consequently, openness and togetherness are regarded as the ‘ideal’ stance to hold and to facilitate in practice (Traa et al., 2015). However, negative consequences of disclosure have also been reported by patients with cancer (Gray et al., 2000; Yoo et al., 2010). Our study underscores the importance of not imposing an expectation of total openness and togetherness on cancer patients as openness may pertain different things for different persons (Goldsmith and Miller, 2014). In this line of thought, nurses must be (re)educated to recognize that topic avoidance can be beneficial if satisfying cancer patients' needs (e.g. other-protection or self-protection) (Parks, 2007). The struggles that patients had in managing supportive relationships and their communication, coupled with their associated feelings of solicitude, indicate the need for offering guidance in handling this. Nurses can regularly question how the patient is dealing with this intricate communication work. To that end, it may be important for nurses to guide patients and family members in letting each other know their actual preferences regarding how and what to communicate (Magsamen-Conrad et al., 2015).

Nurses are well placed to support the ongoing disclosure process of cancer patients by opening up opportunities for discussion during clinical appointments (Munro et al., 2015). Being able as a nurse to engage with the different types of involvement, while also bearing in mind that this involvement may fluctuate over time, seems key in delivering successful oncology care. Nurses might be at risk of upsetting a delicate balance within parent-child relationship and family if they take an approach that is too directive and/or if they prematurely suggest a different role or level of involvement without a grasp of the overall relationship. Our study favours the need of a shift in oncology care from a focus on the individual experience of the patient and the spousal caregiver to a multigenerational family-sensitive perspective (Fletcher et al., 2012). Family meetings (Powazki et al., 2014), genograms and ecomaps (Wright and Leahey, 2013) may be useful tools for unravelling family dynamics and meaning making within families confronted with cancer.

6. Methodological considerations

This study highlights a number of important issues in the under researched area of the views of cancer patients vis-à-vis their older parents. Although already informative for clinical practice, we need to take into account the limitations set by the exploratory nature of the study. An important limitation is the unilateral investigation of an essential interactive process between two (or even more) parties. The next step is to substantiate our findings with data on the perspective of the older parents and with interactional data. Further, the transferability of our findings is limited as they mainly pertain to white, Dutch speaking, articulate, self-reflective breast cancer patients. Data saturation was not reached because of our small sample size. Nonetheless we gained in-depth and rich data. Future research with a larger and more diverse sample is needed to extend knowledge of the perspectives: their development over time, the association of the middle-aged child, parent and social conditions with them and pre-diagnosis relationship quality. Further research would benefit from broadening the descriptive scope to include different cultures, and different types of cancer or illness. Another understudied feature is how patient and parent communication, both open and avoidant, affects both actors' well-being and relational outcomes (both short and long term).

7. Conclusion

Our findings contribute to our understanding of how adult middle-aged cancer patients perceive the relationship with their parents in the midst of the illness trajectory. More concretely, the findings can help nurses understand why cancer patients do not always openly communicate with their parents (and wider environment). Based on our findings, oncological nurses can have a key role in identifying and acknowledging the mechanism of solicitude that grounds the communicative behaviour of cancer patients. Our findings add to research about communication, tensions and the adult child-older parent relationship and offer promising avenues for future research.

Funding

This study was funded by the Flemish League against Cancer (VLK A11/TT/0756).

Conflicts of interest

The authors have no conflicts of interest to disclose.

References

Askham, J., Ferring, D., Lamura, G., 2007. Personal relationships in later life. In: Bond, J., Peace, S.M., Dittman-Kohli, F., Westerhof, G. (Eds.), Ageing in Society: an Introduction to Social Gerontology. SAGE Publications, London, pp. 186–206.

Belgian Cancer Registry, 2018, January 16. Annual Tables. Retrieved from: https://kankerregister.org/Annual%20Tables.

Brandes, K., Linn, A.J., Smit, E.G., van Weert, J.C.M., 2016. Unraveling the determinants of cancer patients' intention to express concerns. J. Health Commun. 21, 327–336.

Caruso, R., Nanni, M.G., Riba, M.B., Sabato, S., Grassi, L., 2017. The burden of psychosocial morbidity related to cancer: patient and family issues. Int. Rev. Psychiatr. 29, 389–402.

Charmaz, K., 2014. Constructing Grounded Theory. SAGE Publications, London.

Copeland, D.A., Heilemann, M.V., 2011. Choosing "the best of the hells": mothers face housing dilemmas for their adult children with mental illness and a history of violence. Qual. Health Res. 21, 520–533.

Donovan-Kicken, E., Tollison, A.C., Goins, E.S., 2012. The nature of communication work during cancer: advancing the theory of illness trajectories. Health Commun. 27, 641–652.

Edvardsson, T., Ahlstrom, G., 2008. Being the next of kin of a person with a low-grade glioma. Psycho Oncol. 17, 584–591.

Edwards, L.L., Donovan-Kicken, E., Reis, J.S., 2014. Communicating in complex situations: a normative approach to HIV-related talk among parents who are HIV+. Health Commun. 29, 364–374.

Fingerman, K., Cheng, Y.P., Birditt, K., Zarit, S., 2012. Only as happy as the least happy child: multiple grown children's problems and successes and middle-aged parents' well-being. J. Gerontol. B Psychol. Sci. Soc. Sci. 67, 184–193.

Fisher, C.L., 2010. Coping with breast cancer across adulthood: emotional support communication in the mother-daughter bond. J. Appl. Commun. Res. 38, 386–411.

Fisher, C.L., Wolf, B.M., Fowler, C., Canzona, M.R., 2017. Experiences of "openness" between mothers and daughters during breast cancer: implications for coping and healthy outcomes. Psycho Oncol. 26 (11), 1872–1880.

Fletcher, B.S., Miaskowski, C., Given, B., Schumacher, K., 2012. The cancer family caregiving experience: an updated and expanded conceptual model. Eur. J. Oncol. Nurs. 16 (4), 387–398.

Goldsmith, D.J., Miller, G.A., 2014. Conceptualizing how couples talk about cancer. Health Commun. 29, 51–63.

Gray, R.E., Fitch, M., Phillips, C., Labrecque, M., Fergus, K., 2000. To tell or not to tell: patterns of disclosure among men with prostate cancer. Psycho Oncol. 9, 273–282.

Gubrium, J.F., Holstein, J.A., Marvasti, A.B., McKinney, K.D., 2012. The Sage Handbook of Interview Research: the Complexity of the Craft. SAGE Publications, Thousand Oaks.

Hendriksen, E., Williams, E., Sporn, N., Greer, J., DeGrange, A., Koopman, C., 2015. Worried together: a qualitative study of shared anxiety in patients with metastatic non-small cell lung cancer and their family caregivers. Support. Care Canc. 23, 1035–1041.

Hilton, S., Emslie, C., Hunt, K., Chapple, A., Ziebland, S., 2009. Disclosing a cancer diagnosis to friends and family: a gendered analysis of young men's and women's experiences. Qual. Health Res. 19, 744–754.

Johansson, A., Ewertzon, M., Andershed, B., Anderzen-Carlsson, A., Nasic, S., Ahlin, A., 2015. Health-related quality of life-From the perspective of mothers and fathers of adult children suffering from long-term mental disorders. Arch. Psychiatr. Nurs. 29, 180–185.

Kershaw, T., Ellis, K.R., Yoon, H., Schafenacker, A., Katapodi, M., Northouse, L., 2015. The interdependence of advanced cancer patients' and their family caregivers' mental health, physical health, and self-efficacy over time. Ann. Behav. Med. 49, 901–911.

Ketokivi, K., 2012. The intimate couple, family and the relational organization of close relationships. Sociology 46, 473–489.

Kim, Y., Shaffer, K.M., Carver, C.S., Cannady, R.S., 2016. Quality of life of family caregivers 8 years after a relative's cancer diagnosis: follow-up of the National Quality of Life Survey for Caregivers. Psycho Oncol. 25, 266–274.

Kim, Y., Wellisch, D.K., Spillers, R.L., 2008. Effects of psychological distress on quality of life of adult daughters and their mothers with cancer. Psycho Oncol. 17, 1129–1136.

Levitzki, N., 2009. To give or not to give, this is the question; Israeli older parents negotiate the provision of support to adult children. Gerontol. 49 361-361.

Lincoln, Y.S., Guba, E.G., 1985. Naturalistic Inquiry. Sage Publications, Thousand Oaks, CA.

Magsamen-Conrad, K., Checton, M.G., Venetis, M.K., Greene, K., 2015. Communication efficacy and couples' cancer management: applying a dyadic appraisal model. Commun. Monogr. 82, 179–200.

Malterud, K., 2001. Qualitative research: standards, challenges, and guidelines. Lancet 358, 483–488.

Manne, S., Myers, S., Ozga, M., Kissane, D., Kashy, D., Rubin, S., Heckman, C., Rosenblum, N., 2014. Holding back sharing concerns, dispositional emotional expressivity, perceived unsupportive responses and distress among women newly diagnosed with gynecological cancers. Gen. Hosp. Psychiatr. 36, 81–87.

Manne, S.L., Norton, T.R., Ostroff, J.S., Winkel, G., Fox, K., Grana, G., 2007. Protective buffering and psychological distress among couples coping with breast cancer: the moderating role of relationship satisfaction. J. Fam. Psychol. 21, 380–388.

Miller, L.E., 2014. Communication dilemmas in the context of cancer: survivors' and partners' strategies for communicating throughout survivorship. Issues Ment. Health Nurs. 35, 914–923.

Munro, H., Scott, S.E., King, A., Grunfeld, E.A., 2015. Patterns and predictors of disclosure of a diagnosis of cancer. Psycho Oncol. 24, 508–514.

Northouse, L., Williams, A.L., Given, B., McCorkle, R., 2012. Psychosocial care for family caregivers of patients with cancer. J. Clin. Oncol. 30, 1227–1234.

Parks, M.R., 2007. Personal Relationships and Personal Networks. Erlbaum, Mahwah.

Petronio, S., 2002. Boundaries of Privacy: Dialectics of Disclosure. SUNY Press, New York.

Powazki, R., Walsh, D., Hauser, K., Davis, M.P., 2014. Communication in palliative medicine: a clinical review of family conferences. J. Palliat. Med. 17 (10), 1167–1177.

Pryce, L., Tweed, A., Hilton, A., Priest, H.M., 2017. Tolerating uncertainty: perceptions of the tuture for ageing parent carers and their adult children with intellectual disabilities. J. Appl. Res. Intellect. Disabil. 30, 84–96.

Raveis, V.H., Pretter, S., 2005. Existential plight of adult daughters following their mother's breast cancer diagnosis. Psycho Oncol. 14, 49–60.

Rozer, J., Mollenhorst, G., Poortman, A.R., 2016. Family and friends: which types of personal relationships go together in a network? Soc. Indicat. Res. 127, 809–826.

Selman, L.E., Beynon, T., Radcliffe, E., Whittaker, S., Orlowska, D., Child, F., Harding, R., 2015. 'We're all carrying a burden that we're not sharing': a qualitative study of the impact of cutaneous T-cell lymphoma on the family. Br. J. Dermatol. 172, 1581–1592.

Senden, C., Vandecasteele, T., Vandenberghe, E., Versluys, K., Piers, R., Grypdonck, M., Van Den Noortgate, N., 2015. The interaction between lived experiences of older patients and their family caregivers confronted with a cancer diagnosis and treatment: a qualitative study. Int. J. Nurs. Stud. 52, 197–206.

Sulkers, E., Tissing, W.J., Brinksma, A., Roodbol, P.F., Kamps, W.A., Stewart, R.E., Sanderman, R., Fleer, J., 2015. Providing care to a child with cancer: a longitudinal study on the course, predictors, and impact of caregiving stress during the first year after diagnosis. Psycho Oncol. 24, 318–324.

Tong, A., Sainsbury, P., Craig, J., 2007. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int. J. Qual. Health Care 19, 349–357.

Traa, M.J., De Vries, J., Bodenmann, G., Den Oudsten, B.L., 2015. Dyadic coping and relationship functioning in couples coping with cancer: a systematic review. Br. J. Health Psychol. 20, 85–114.

Ungerson, C., 1987. Policy Is Personal: Sex, Gender and Informal Care. Tavistock, London.

Van Humbeeck, L., Piers, R.D., S, V.C., Dillen, L., Verhaeghe, S.T., Van Den Noortgate, N.J., 2013. Aged parents' experiences during a critical illness trajectory and after the death of an adult child: a review of the literature. Palliat. Med. 27 (7), 583–595.

Van Humbeeck, L., Dillen, L., Piers, R.D., Grypdonck, M., Verhaeghe, S.T.L., Van Den Noortgate, N., 2015. Tightrope walkers suffering in silence: a qualitative study into the experiences of older parents who have an adult child with cancer. Int. J. Nurs. Stud. 52 (9), 1445–1453.

Ward, R.A., 2008. Multiple parent-adult child relations and well-being in middle and later life. J. Gerontol. B Psychol. Sci. Soc. Sci. 63, S239–S247.

Wright, L.M., Leahey, M., 2013. Nurses and Families: a Guide to Family Assessment and Intervention. Philadelphia: F.a. Davis.

Yoo, G.J., Aviv, C., Levine, E.G., Ewing, C., Au, A., 2010. Emotion work: disclosing cancer. Support. Care Canc. 18, 205–215.

Zhang, A.Y., Siminoff, L.A., 2003. Silence and cancer: why do families and patients fail to communicate? Health Commun. 15, 415–429.