

## PAPER

# The construction of help during radiotherapy: Redefining informal care

Lynda Appleton<sup>1</sup>  | Elizabeth Perkins<sup>2</sup> 

<sup>1</sup>The Clatterbridge Cancer Centre NHS Foundation Trust, Bebington, Wirral, UK

<sup>2</sup>Institute of Psychology, Health and Society, William Rathbone VI Chair of Community Nursing Research, University of Liverpool, Liverpool, UK

**Correspondence**

Lynda Appleton, Research Nurse, The Clatterbridge Cancer Centre NHS Foundation Trust, Clatterbridge Road, Bebington, Wirral, CH63 4JY, UK.

Email: lynda.appleton@clatterbridgecc.nhs.uk

**Abstract**

**Objectives:** This study will explore how help is constructed during and following radiotherapy for patients with cancer.

**Methods:** Grounded theory methods were used in the study to explore the way in which family members and friends constructed a role for themselves in relation to patients receiving radiotherapy. A total of 22 helpers were interviewed. Patients were being treated for a range of cancers including breast, prostate, colorectal, and head and neck.

**Results:** Respondents in this study consistently defined themselves as “helpers” rather than “carers.” While radiotherapy as a treatment modality was mostly seen as noninvasive, the cancer diagnosis cast a long shadow over the lives of helpers and patients creating a separation in longstanding relationships. Helpers experienced this separation as “otherness.” Help became an important vehicle for bridging this separation. Individuals developed different ways of knowing about the patient as the basis for providing help. Two different types of help were identified in this study: the behind the scenes, largely invisible work that helpers undertook to help the patient without their knowledge and the explicit visible help that was much more commonly negotiated and discussed between helpers and patients.

**Conclusions:** The study provides the basis for a greater understanding on the part of professionals into the impact of diagnosis and radiotherapy treatment on family and friends. In doing so, the study identifies opportunities for the experience of helpers to be recognised and supported by professionals.

**KEYWORDS**

cancer, help, informal care, oncology, qualitative research, radiotherapy

## 1 | BACKGROUND

There are currently 6.5 million people in the United Kingdom defined as providing informal care to patients across a range of ages and conditions, which is set to increase to 9 million by 2037, with an estimated 1.4 million carers providing over 50 hours of unpaid care per week.<sup>1</sup> Typically, informal carers comprise family members and friends or neighbours who provide practical assistance or emotional support to a person who has been diagnosed with a health condition.<sup>2</sup> Numerous studies have investigated the impact of providing informal care on the physical and psychological health of the individual. In the literature, the role of the carer is often described as challenging and demanding, arising from tasks undertaken on behalf of the patient such as practical help with meals or shopping, supervision, or taking them out.<sup>2-5</sup>

Health care professionals commonly use terminology such as informal carer or caregiver to identify family members who support the patient. However, the terminology surrounding informal care has the potential to create both barriers and opportunities for access to support and resources. Henderson and Forbat<sup>6</sup> suggest that informal care has become conceptualised as a narrowly defined phenomenon linked to the experiences and needs of carers, rather than the broader social and cultural context of caring embedded in relationships, identity, and gender.<sup>7</sup> Dominant policy discourses continue to frame care as the responsibility of women, assuming them to be available and willing to care,<sup>8</sup> while medical and social narratives focus on professional interventions to sustain the informal care role.<sup>9</sup>

Traditionally, the language used to describe informal care has failed to capture the complex and mutual nature of help as a

relationship-based activity founded on commitment, instead framing carers as coworkers and passive recipients of professional support.<sup>10-12</sup> There is evidence to suggest that the term “carer” polarises the needs of the carer and patient and only reflects a small part of the identity of those providing care.<sup>6,7</sup> A UK study by Hughes et al.<sup>12</sup> suggested that siblings were more inclined to accept the identity of carer compared to spouses who lived with the patient and who expected to provide care.

Few studies have explored the way care is constructed, delivered, and managed during the patient's radiotherapy. This is surprising since radiotherapy is one of the main treatments for cancer patients, with 40% of patients being treated with this modality.<sup>13</sup> While the treatment is known to have an effect on the patient in terms of their physical and emotional health, the impact on the person helping is less known.<sup>14</sup> A few studies focus on the structural and organisational impact of radiotherapy on the daily life of people living with patients receiving radiotherapy, e.g., through assistance with transport and parking.<sup>15</sup> Moderate to high levels of unmet psychological need associated with increased responsibility for household tasks as a result of radiotherapy schedules have been reported in a study undertaken in Australia by Clavarino et al.<sup>16</sup>

The aim of the present study was to explore how family and friends constructed and negotiated their role during the patient's radiotherapy.

## 2 | METHODS

The study was designed as a qualitative study using the principles of grounded theory.<sup>17</sup> Interviews were conducted with people providing help and support to patients undergoing radiotherapy. The interviews were designed to identify the nature of their interactions, experiences and coping mechanisms, and the skills and knowledge they drew on to inform, manage, and deliver their role to the patient.

## 3 | SAMPLING

Twenty-two participants were recruited through patients attending a regional cancer centre for radical external beam radiotherapy to breast, prostate, head and neck, and colorectal cancer. Patients were invited to identify the person from whom they received the most care and support (participant characteristics are summarised in Table 1). Three interviews were conducted with each participant at different time points: (1) prior to the patient's radiotherapy, (2) during the patient's radiotherapy (approximately midway), and (3) 3 to 4 months following completion of the patient's radiotherapy. A total of 57 interviews were completed. Full written consent was taken from each participant before the start of the interview, with process consent procedures being followed throughout the study to respond to any changes in personal circumstances over time. Ethical permission was obtained from the Local Research Ethics Committee (reference: 07/Q1403/3) and participating NHS Trust.

**TABLE 1** Participant characteristics

Patient's Cancer Diagnosis (n = 20)	Breast (n = 4) <sup>a</sup>	Prostate (n = 5)	Colorectal (n = 7) <sup>a</sup>	Head & Neck (n = 4)
Treatment intent				
Curative	4	5	4	4
Palliative	-	-	3	-
Relationship to patient				
Spouse	2	5	5	4
Sibling	3	-	1	-
Mother	-	-	1	-
Friend	-	-	1	-
Gender				
Female	3	5	6	3
Male	2	-	2	1
Age range, years				
18-35	-	-	1	-
36-65	4	3	5	4
66+	1	2	2	-
Employment status				
Retired	1	4	5	1
Not working	1	1	1	-
In work	3	-	2	3
Children				
Yes	2	-	1	1
No	3	5	7	3
No. of interviews completed				
Preradiotherapy	5	5	6 <sup>b</sup>	2 <sup>b</sup>
Midradiotherapy	5	5	6 <sup>b</sup>	2 <sup>b</sup>
3- to 4-month postradiotherapy	5	5	8	3 <sup>b</sup>

<sup>a</sup>More than one helper was interviewed for some patients.

<sup>b</sup>Not all helpers were interviewed at this time-point.

## 4 | DATA COLLECTION

Interviews were conducted by a single researcher using an interview guide, which evolved over the course of the interviews. The interviews covered the patient's physical/emotional health, the impact of radiotherapy on the lives of family and friends of the patient, and the nature of the exchanges which took place before and during radiotherapy. Interviews were mainly conducted in participants' homes and were audio recorded.

## 5 | DATA ANALYSIS

The initial interviews were coded line-by-line. Codes were created for data segments according to their meaning, action, or key issue. As the number of interviews increased, codes with similar meanings were identified and clustered into categories. The categories were then labelled with a heading that reflected the conceptual nature of the data grouping, which was usually more abstract than the original code. Similarities and differences between codes and categories were recorded through constant comparison between

and within the transcripts. Data were analysed by both authors, individually and together to ensure the process was rigorous and systematic and to check interpretations and coding of the data as the study progressed.

## 6 | FINDINGS

The concept of “help” was used by all participants to define their role in relation to the patient in the context of radiotherapy. Four main themes relating to the construction of help were identified: “otherness”, “ways of knowing”, “invisible help,” and “explicit help.”

## 7 | OTHERNESS

For many helpers, the cancer diagnosis inserted a wedge into the relationship, disrupting normal patterns of communication and creating a distance. Being outside the patient's illness created a sense of powerlessness in the helper; from the vantage point of being well, it was difficult to know much about what it was actually like to have the diagnosis: “It's easy for me to say 'cos I'm, you know what I mean, I'm not taking the treatment” P07/1. The concept of “otherness” provided the foundation for understanding the experience of being different from the patient by virtue of the cancer diagnosis. Being on the outside of a cancer diagnosis, that is, not being the person diagnosed with cancer but connected to the person diagnosed with it, is rarely discussed in the research literature. Changes in the patient's behaviour accompanying the diagnosis and treatment reinforced this sense of otherness. Helpers reported not recognising aspects of the patient's behaviour, which emerged in the context of the diagnosis: “He's quite moody, he's changed from being a normal person that he is, but obviously it's the pain that he's going through” P15/1. Helpers reported difficulties adjusting to the negative aspects of the patient's behaviour, even though they made attempts to explain away or understand the behaviours as a product of the diagnosis. Helpers also felt excluded when patients withheld information about how they felt, either physically or emotionally: “I don't know whether he is just saying that to sort of calm me down, please me, or whether he really believes it” P06/2.

## 8 | WAYS OF KNOWING

The experience of being outside the patient's disease created the need to develop methods for understanding and interpreting how help might be given. Individuals viewed their role as helping and supporting the patient, as opposed to providing them with care: “I don't see myself as caring for her, I help her to cope” P17/1. Care was most often viewed as resulting from the need for physical support, as one participant explained: “When I think of the word carer, I think of somebody that's looking after somebody that physically can't do something, so physically needs support” P01/3. In this study, helpers viewed “care” as something that was provided by services rather than family members: “You don't see yourself as being a carer, if you like, a carer, you think of district nurses coming out into

the community caring for somebody, somebody else from the outside coming in” P11/1. Help was grafted onto precancer relationships and routines and was viewed as a normal part of daily business, as these quotes illustrate: “It's my obligation as her husband, it's my job to do that ... that's what I'm here for really, for better or for worse” P14/3 and “I would never say I am a carer I am her mum and I would do it because I am a mum, cause I brought her into this world” P19/1. Helpers engaged in a number of activities to put themselves in the best place to provide help, which involved monitoring the patient, drawing on knowledge of the patient's character, and seeking out information from multiple sources such as the internet and treatment centre. As these two quotes illustrate, the patient was monitored both overtly and covertly: “I shall be watching him but trying not to look yes, trying not to look at him” P10/1 and “I asked her the other day if she was feeling normal, back to the way she felt before she had the cancer” P01/2.

Becoming informed about the effects of radiotherapy provided a way to cope with the impact of cancer on daily life, as well as a way of working out what to do for the best. One helper suggested that good information was a powerful weapon in managing the cancer: “You fight it with information ... you try and be realistic” P09/2, and placed trust and confidence in professionals for providing accurate and reliable information: “They're the experts ... they're in the driving seat” P15/2. In comparison with chemotherapy, radiotherapy was not anticipated to be as toxic or as invasive: “I am not expecting him to be sick or anything like that ... in my mind that's the chemo” P06/1. As radiotherapy progressed, helpers returned to the idea that radiotherapy did not appear to be making the patient ill: “When you find out the treatment isn't making you poorly like chemo does ... radiotherapy fortunately doesn't have that effect” P06/3. Radiotherapy was seen to be working almost invisibly: “There's nothing sort of err, in your face about radiotherapy” P03/2 and “It is strange ... you could almost pretend it hadn't happened except it did” P09/3.

## 9 | THE INVISIBLE HAND OF HELP

The invisible hand of help represented the behind the scenes work that helpers undertook, privately, away from the person at whom the help was directed and without their direct involvement. Helpers acted to modify the patient's environment through strategies designed to minimise potential problems and enable the patient to live as easily as possible within the knowledge of a life-threatening condition. Many helpers reported using diaries and keeping mental notes to keep their lives running as normal while radiotherapy was in progress. As one participant reported: “We're trying to get that balance between acting as though nothing's going on, as if you can with all the disruption and keeping a social life going” P09/1. Carrying on as normal was contingent on finding a way to get on with the job of providing help.

The majority of helpers expended considerable energy in trying to protect the patient from negative influences that could undermine their physical and emotional well-being. Action was taken to deflect situations or responses that were construed as harmful or distressing before they reached the patient. One helper sought to manage

conversations with the patient: "I try and change the subject because I just don't think that's healthy" P13/2, while another helper placed priority on keeping the patient's spirits up and cajoling them into a positive state of mind: "You have got to constantly pick them up" P11/1. Maintaining this positive outlook often required helpers to suppress their own concerns and anxieties as they were not considered conducive to the patient's recovery: "As I say you have got no option, you have to be alright, I can't fall apart because if I fall, apart it's going to upset him, it's going to make him worse" P07/1.

## 10 | EXPLICIT HELP

In contrast with the behind the scenes help, a substantial component of the help that was offered was both negotiated and explicit. Explicit help was aimed at practical and tangible support to make the patient's life easier while they were receiving radiotherapy. Typically, explicit help involved getting the patient organised to receive their treatment and managing people who were involved in the process such as family and friends. Keeping the patient company throughout treatment enabled help to be delivered through the gathering and processing of information aimed at promoting the patient's recovery. One helper reported that attending radiotherapy with the patient was important: "So I know as much as she knows and if we're discussing it, we know what each other are talking about" P01/2.

Accommodating radiotherapy into daily life required setting aside other commitments and prioritising the radiotherapy schedule. Helpers often engaged in altering plans and reorganising activities to be present during the patient's daily visits to the treatment centre: "I know in my heart that I've made the right decision cancelling the work to be here for her" P17/1. Being present allowed helpers to show solidarity and support for the patient in a highly tangible way: "It's all you can do is sit there, waiting for them, talk them through, listen, I am not sure what else you can actually do, unless that person, unless somebody has a specific need you can meet" P09/3. Some helpers were unable to juggle their multiple roles, and in one case, this prevented the helper from attending the patient's radiotherapy: "I can't go because I was looking after the kids ... and I don't drive" P18/1.

Explicit help involved managing the environment, sustaining nutritional intake, and reducing pain and discomfort. One helper described purchasing food the patient would enjoy: "I keep buying things when I am out, going 'I thought you might like this, you might fancy that', and you are just constantly trying to find food" P16/1, while another helper tried to manage the patient's work: "I think the key of it is taking the business away from her, you know, taking the phones away and making the house quiet" P14/3.

The longitudinal element of the study revealed some changes in the way radiotherapy was anticipated, experienced, and reflected upon as the patient transitioned to the new normal on completion of treatment. Both visible and invisible help were identified at each of the time points at which interviews were conducted. While the longitudinal data did not reveal any new concepts, the emphasis on key components of help changed over time. Key aspects of diagnosis and treatment featured as disruptions, which required adjustment in everyday activities and in the relationship between the patient and

those providing help. Over time, these adjustments became a new way of being and were referred to as new normalities. The routine nature of radiotherapy treatment created a new structure for week day living. However, as the radiotherapy treatment progressed and the end of treatment came into view, participants began to anticipate another kind of everyday life without radiotherapy. While this was often talked about in terms of "getting their lives back," it was clear that the lives that were being talked about had been fundamentally changed by the experience of the diagnosis and treatment.

## 11 | DISCUSSION

This study challenges the dominant political, social, and medical discourses surrounding the phenomena of informal care by suggesting that family and friends whom health professionals might label as informal carers see themselves predominately as helpers. This study illustrates the multidimensional and complex nature of help and some of the difficulties that helpers experience in finding a way to provide support to a patient diagnosed with cancer.

All helpers in this study identified a change in the relationship with the patient following the cancer diagnosis, and help was seen as a way of bridging this change. The occurrence of cancer within the relationship required both the patient and helper to deal with the implications of this and the possibility of bodily control being lost and ultimately death. Frank<sup>18</sup> describes how illness, including cancer, alters the basis of relationships as the helper can never truly understand the experience of the patient because they do not have the disease. The impact of illness on relationships may be further accentuated if the patient cuts themselves off from the helper to regulate and manage their situation alone. In this study, the strategies and skills that were required by the helper to provide help to the patient were new. Helpers sought to maximise the patient's survival and recovery through a series of actions involving the "re-drawing of maps and search for new destinations"<sup>18</sup> (p. 53). Radiotherapy disrupted everyday routines, but not the bodily integrity of the patient. In line with Goffman's<sup>19</sup> assertion that individuals are responsible for the way they present themselves and manifest the signs of their illness, it was possible for the patient's in this study to conceal their altered identity from public view.

Coming to terms with the patient's cancer diagnosis was not easy and required the mobilisation of resources, knowledge, and skills to deal with the situation, although these were rarely reported to have been openly discussed with the patient or health care professionals. A core component in the construction of help was the gathering of information from a range of sources such as medical information, prior experiential knowledge and public/media accounts. These strategies highlight how information enables helpers to feel prepared, to know what to expect and to feel confident in delivering help and are widely reported in the literature.<sup>20,21</sup>

Two different dimensions of helping were identified by individuals in this study: invisible help and explicit, visible help. Invisible help was largely defined through the actions helpers took to protect the patient from negative influences by shaping the patient's environment without their knowledge. Helpers maintained an explicit and optimistic tone of

hopefulness, regardless of how they felt inside. Focusing on the positive throughout the patient's disease and treatment pathway is known to enable adjustment and coping in a challenging situation.<sup>22-24</sup> Invisible help encompassed activities intended to shape the patient's environment to make delivery and receipt of help easier. This was achieved through measures directed at keeping life in order, screening out negativity, and placing the patient as the focal point for attention. This finding is mirrored in other studies<sup>25-27</sup> where individuals engage in complex emotion work, suggesting the need for further study on the way resilience and coping strategies are mobilised by helpers. In contrast, visible, explicit help focused on activities that were tangible and practical. For many helpers, accompanying the patient to clinic appointments provided them with a role and a sense of satisfaction that something could be done to support the patient practically. It also afforded them the opportunity to ask questions and clarify information. This has been identified by other researchers as important to the management of the patient.<sup>28,29</sup>

While some activities were put on hold, other life events carried on alongside radiotherapy or were coordinated differently to accommodate radiotherapy. The sacrifices helpers make to support the patient through treatment are well recorded in the literature<sup>30-32</sup>; however, the complex emotional demands placed upon helpers in managing the provision of help both invisibly and through explicit activities are rarely acknowledged in practice.

## 12 | STUDY LIMITATIONS

This study has highlighted the hitherto poorly understood concept of help in the context of cancer. The construction of help in this study is based on narratives from participants over a number of months. The data were rigorously analysed aided by the use of memos and a field diary, taking into account the importance of reflexivity and sticking close to the participants' narratives. However, the majority of participants were female, spouses, and siblings to the patient. Friends, parents, and children were not well represented in the sample. While this may be a reflection of the demographic reality of the cancer diagnosis, it does limit the scope of these findings.

## 13 | CLINICAL IMPLICATIONS

This study suggests that people who provide help to the patient undergoing radiotherapy may themselves require help. This study has highlighted the complex ways in which helpers construct a role for themselves through the direct provision of help and support as well as through managing and organising various aspects of the patient's life. Much like people who define themselves as informal carers, these activities are often undertaken in isolation and require complex psychological work. The nature of the work undertaken by helpers appears to have rarely attracted the attention of the health professionals dealing with the patient and this is reinforced by the construction of their work as help rather than care. Health care workers need to access the language of help as well as care if they wish to truly understand the home circumstances in which patients are cared for. Understanding the complex nature of help will enable health

professionals to explore with helpers their role and identify services which might support them in this role. There may be a risk that the stresses and difficulties of supporting patients undergoing radiotherapy go unidentified if health professionals focus on care rather than help.

## ACKNOWLEDGEMENTS

This study was supported through funding from the host NHS organisation. Special thanks are extended to my supervisor, Professor Elizabeth Perkins, for her continuous support throughout my PhD study. We express our deepest gratitude to all the study participants who so willingly gave up their time to take part in the study. The authors know of no conflict of interests relating to this work.

## REFERENCES

1. Carers UK. *Facts About Carers, Policy Briefing*. London: Carers UK; 2014.
2. The Health and Social Care Information Centre. *Survey of Carers in Households 2009/10*. Leeds, England: The NHS Information Centre for Health and Social Care; 2010.
3. Deshields T, Rihanek A, Potter P, et al. Psychosocial aspects of caregiving: perceptions of cancer patients and family caregivers. *Support Care Cancer*. 2012;20(2):349-356.
4. Ugalde A, Krishnasamy M, Schofield P. Role recognition and changes to self-identity in family caregivers of people with advanced cancer: a qualitative study. *Support Care Cancer*. 2012;20(6):1175-1181.
5. Dunn LB, Aouizerat BE, Cooper BA, et al. Trajectories of anxiety in oncology patients and family caregivers during and after radiation therapy. *Eur J Oncol Nurs*. 2012;16:1-9.
6. Henderson J, Forbat L. Relationship-based social policy: personal and policy constructions of 'care'. *Crit Soc Pol*. 2002;22(4):669-687.
7. Ussher JM, Sandoval M. Gender differences in the construction and experience of cancer care: the consequences of the gendered positioning of carers. *Psychol Health*. 2008;23(8):945-963.
8. Williams A. Changing geographies of care: employing the concept of therapeutic landscapes as a framework in examining home space. *Soc Sci Med*. 2002;55:141-154.
9. Fine M, Glendinning C. Dependence, independence or inter-dependence? Revisiting the concepts of 'care' and 'dependency'. *Ageing Soc*. 2005;25(4):601-621.
10. Molyneux V, Butchard S, Simpson J, Murray C. Reconsidering the term 'carer': a critique of the universal adoption of the term 'carer'. *Ageing Soc*. 2011;31:422.
11. Davies JC. Preserving the "us identity" through marriage commitment while living with early-stage dementia. *Dementia: Int J Soc Res Pract*. 2011;10(2):217-234.
12. Hughes N, Locock L, Ziebland S. Personal identity and the role of 'carer' among relatives and friends of people with multiple sclerosis. *Soc Sci Med*. 2013;96:78-85.
13. Cancer Research UK. What radiotherapy is. Available at: <http://www.cancerresearchuk.org/about-cancer/cancers-in-general/treatment/radiotherapy/about/what-radiotherapy-is> (Accessed: 04/01/2016).
14. Fitch MI, Gray RE, McGowan T, et al. Travelling for radiation cancer treatment: Patient perspectives. *Psychooncology*. 2003;12:664-674.
15. Thomas C, Morris SM, Harman JC. Companions through cancer: the care given by informal carers in cancer contexts. *Soc Sci Med*. 2002;54:529-544.
16. Clavarino AM, Lowe JB, Carmont S, Balanda K. The needs of cancer patients and their families from rural and remote areas of Queensland. *Aust J Rural Health*. 2002;10:188-195.

17. Glaser BG, Strauss AL. In: Glaser BG, Strauss AL, eds. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New Brunswick, NJ: Aldine Transaction; 1967.
18. Frank AW. *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: University of Chicago Press; 1995.
19. Goffman E. *The Presentation of Self in Everyday Life*. A 174 Garden City, N.Y.: Doubleday anchor books; 1959.
20. Harrop E, Byrne A, Nelson A. It's alright to ask for help: findings from a qualitative study exploring the information and support needs of family carers at the end of life. *BMC Palliat Care*. 2014;13(1):1-17.
21. Brereton L, Nolan M. 'Seeking': a key activity for new family carers of stroke survivors. *J Clin Nurs*. 2002;11(1):22-31.
22. Kennedy P, Evans M, Sandhu N. Psychological adjustment to spinal cord injury: the contribution of coping, hope and cognitive appraisals. *Psychol Health Med*. 2009;14(1):17-33.
23. Dorsett P. The importance of hope in coping with severe acquired disability. *Aust Soc Work*. 2010;63(1):83-102.
24. Wu HC. The protective effects of resilience and hope on quality of life of the families coping with the criminal traumatising of one of its members. *J Clin Nurs*. 2011;20(13):1906-1915.
25. Thomas C, Morris SM. Informal carers in cancer contexts. *Eur J Cancer Care*. 2002;11(3):178-182.
26. Morse JM, Wilson S, Penrod J. Mothers and their disabled children: refining the concept of normalization. *Health Care Women Int*. 2000;21(8):659-676.
27. Sanderson T, Calnan M, Morris M, Richards P, Hewlett S. Shifting normalities: interactions of changing conceptions of a normal life and the normalisation of symptoms in rheumatoid arthritis. *Sociol Health Illn*. 2011;33(4):618-633.
28. Rees CE, Bath PA, Lloyd-Williams M. The information concerns of spouses of women with breast cancer: patients' and spouses' perspectives. *J Adv Nurs*. 1998;28(6):1249-1258.
29. DuBenske LL, Chih MY, Gustafson DH, Dinauer S, Cleary JF. Caregivers' participation in the oncology clinic visit mediates the relationship between their information competence and their need fulfillment and clinic visit satisfaction. *Patient Educ Couns*. 2010;81: S94-S99.
30. Rubin, P. *Cured II, LENT: Cancer Survivorship Research and Education : Late Effects on Normal Tissues / P. Rubin ... [et al.]; with contributions by M.J. Adams ... [et al.]; forward by L.W. Brady ... [et al.]*, New York; Springer; 2008.
31. Lee C, Ho C. Post-treatment late complications of nasopharyngeal carcinoma. *Eur Arch Otorhinolaryngol*. 2012;269(11):2401-2409.
32. Quon H, Cheung PC, Loblaw DA, et al. Clinical investigation: hypofractionated concomitant intensity-modulated radiotherapy boost for high-risk prostate cancer: late toxicity. *Int J Radiat Oncol Biol Phys*. 2012;82(2):898-905.

**How to cite this article:** Appleton L, Perkins E. The construction of help during radiotherapy: Redefining informal care. *Psycho-Oncology*. 2017. <https://doi.org/10.1002/pon.4420>