

# Typologies for restructuring relationships in cancer survivorship: temporal changes in social support and engagement with self-management practices

Henshall, Catherine; Greenfield, Sheila; Gale, Nicola

DOI:

[10.1097/NCC.0000000000000538](https://doi.org/10.1097/NCC.0000000000000538)

License:

None: All rights reserved

*Document Version*

Peer reviewed version

*Citation for published version (Harvard):*

Henshall, C, Greenfield, S & Gale, N 2017, 'Typologies for restructuring relationships in cancer survivorship: temporal changes in social support and engagement with self-management practices', *Cancer Nursing*, <https://doi.org/10.1097/NCC.0000000000000538>

[Link to publication on Research at Birmingham portal](#)

## **Publisher Rights Statement:**

Final Version of Record published as: Henshall, Catherine L., Sheila M. Greenfield, and Nicola K. Gale. "Typologies for Restructuring Relationships in Cancer Survivorship: Temporal Changes in Social Support and Engagement With Self-Management Practices." *Cancer Nursing* (2017).

Available at: <http://dx.doi.org/10.1097/NCC.0000000000000538>

## **General rights**

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

- Users may freely distribute the URL that is used to identify this publication.
- Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
- User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

## **Take down policy**

While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact [UBIRA@lists.bham.ac.uk](mailto:UBIRA@lists.bham.ac.uk) providing details and we will remove access to the work immediately and investigate.

# **Typologies for restructuring relationships in cancer survivorship: temporal changes in social support and engagement with self- management practices**

Catherine L. Henshall, PhD; Sheila M. Greenfield, PhD; Nicola K. Gale, PhD

Author Affiliations: OxINMAHR, Faculty of Health & Life Sciences, Oxford Brookes University, Oxford, United Kingdom (Dr Henshall); Institute of Applied Health Research, University of Birmingham, Birmingham, United Kingdom (Prof Greenfield); and Health Services Management Centre, University of Birmingham, Birmingham, UK (Dr Gale)

Correspondence: Catherine L. Henshall, PhD, OxINMAHR, Oxford Brookes University, Faculty of Health & Life Sciences, The Colonnade, Gypsy Lane, Headington, Oxford OX3 0BP, United Kingdom and NIHR Oxford cognitive health Clinical Research Facility, Warneford Hospital Oxford, OX3 7JX, United Kingdom (chenshall@brookes.ac.uk)

Funding: This study has been funded by the National Institute for Health Research

Conflicts of Interest: The authors have no conflicts of interest to disclose

**Please cite as:** Henshall, C. L., Greenfield, S. M., & Gale, N. K. (2017). Typologies for Restructuring Relationships in Cancer Survivorship: Temporal Changes in Social Support and Engagement With Self-Management Practices. *Cancer Nursing*. doi: 10.1097/NCC.0000000000000538

**Background:** Cancer survivors with good social support are generally more motivated to undertake self-management behaviors and make lifestyle changes. However, the impact of changes in social support over time, from pre-diagnosis, through treatment and into survivorship, on the health and recovery of cancer survivors with a range of cancer diagnoses has not been explored.

**Objectives:** To examine how temporal changes in social support offered to cancer survivors by family and friends influences their engagement with self-management practices and adaptation to lifestyle changes.

**Methods:** The interview study took place in a teaching hospital in the West Midlands, United Kingdom. Forty participants were purposively sampled. A narrative approach to data collection was chosen and data were thematically analyzed.

**Results:** Six typologies of restructuring relationships post-cancer were identified. A greater understanding of the changes to social relationships that a cancer diagnosis can incur and the impact of this on people's outlook and ability to self-manage was developed.

**Conclusions:** The restructuring of social relationships by cancer survivors over time can impact their outlook and ability to self-manage in survivorship, shaping their engagement with health promoting activities and reconciling cancer within the wider context of their lives.

**Implications for Practice:** Appropriate clinical nursing processes and tailored interventions are required to support cancer survivors and promote engagement with self-management practices. Nurses are a vital component of the social support that enables patients to make the best health and lifestyle choices available to them.

## **Background**

This article contributes to two main areas of the literature on cancer survivorship that are relevant to nursing: 1) the nature of the relationship changes that cancer survivors' experience can impact their health, well-being and recovery; and 2) the importance of self-management (SM) in the survivorship stage of cancer. The following critical appraisal of the current literature identifies gaps and, in particular, the need to draw together our understanding of these two areas through new theoretically-informed empirical research, to enhance nursing support for cancer survivors.

### **The concept of social support in health and recovery**

Social support can be defined as the 'psychological and material resources intended to benefit an individual's ability to cope' <sup>1</sup> and has been conceptualized as a mechanism for promoting positive attitudes towards people's health and lifestyle. Its benefits to physical and mental well-being have been demonstrated in multiple research studies <sup>2-4</sup>. The 'buffering' hypothesis suggests that positive social relationships and networks are linked to improved health <sup>5</sup>, as they buffer the unwanted health consequences caused by stressful life events <sup>6</sup>. As such, psychosocial stress is most damaging to the health and well-being of those with little or no social support <sup>7</sup>. The impact of social support on health and recovery has been explored in relation to long-term conditions (LTCs) such as diabetes <sup>8,9</sup> and in breast and thyroid cancer patients <sup>10-12</sup>. However, the impact of social support over time on the health and recovery of *cancer survivors* with a range of cancer diagnoses has not been explored and is the focus here.

Social support is typically divided into four subtypes; emotional, instrumental, appraisal and informational<sup>13</sup>. Each may provide different buffering effects, depending on the stress experienced<sup>14</sup>. Emotional support relates to the intangible help experienced through love, care and empathy from others<sup>13, 15</sup> and is linked to improved psychological adjustment to cancer<sup>16</sup>. Instrumental support relates to aid and assistance with tangible needs such as cooking or financial aid; appraisal support is relevant to self-evaluation and decision-making, while informational support relates to the provision of information and help with problem-solving<sup>13, 15</sup>. Cancer survivors may experience relationship changes as they reassess them and observe how others respond to their cancer diagnosis, impacting on the type of support they can access. This may influence their ability to cope with, adjust to and manage their disease<sup>10, 17-20</sup>. However, none of the published articles offer a full assessment of the range of relationship changes that can occur, including how they change, from pre-diagnosis, through treatment and into survivorship.

### **Self-management in survivorship**

Successful treatment of cancer as a LTC requires a focus on its management over time, to slow down disease impairments, improve quality of life<sup>21</sup> and give cancer survivors the knowledge, skills and confidence to self-manage aspects of their condition that do not need medical intervention<sup>22, 23</sup>. Cancer survivors are at increased risk of secondary health problems, such as fatigue, anxiety, depression, nausea and pain<sup>24-26</sup>; yet limited advice, support and resources are available to help them manage their condition<sup>27</sup>. Concurrently, increasing financial pressure on healthcare systems leaves nurses short of time, skills and resources to adequately address their requirements<sup>28</sup>. As a result, many cancer survivors report feeling isolated after the end of their active cancer treatment and depression and anxiety can be intensified<sup>27</sup>. This increase in mental

health problems, alongside concurrent physical morbidities<sup>29</sup>, highlights the need for strategies to improve holistic health. Recent policies and guidelines<sup>30-32</sup> have focused on the widespread adoption of integrated and new models of care to meet the needs of a changing population<sup>30</sup> and to optimize the care of those with LTCs, based on their health priorities, lifestyles and goals<sup>31</sup>.

### **Links between social support and self-management**

Family and friends provide key support to people with LTCs; those with more support report less morbidity and mortality, more positive health outcomes and protective health effects<sup>33, 34</sup>. Quantitative and qualitative research suggests those with access to much support from family and friends are generally more motivated to undertake SM behaviors and make healthy lifestyle changes<sup>8-11, 20, 35, 33, 36, 37</sup>, whereas those with low levels of support are more at risk of low self-efficacy to self-manage their health<sup>38</sup>. This evidence is supported by the<sup>39, 40</sup> newly developed Practical Reviews in SM Support (PRISMS) taxonomy, which identifies facilitation of social support as a distinct component of SM support for people with LTCs<sup>23</sup>.

While connections between social support and SM might seem inevitable, much evidence around social support and SM has focused on LTCs apart from cancer<sup>8, 9, 35, 39, 40</sup>. Cancer survivors experience many similar challenges to others with LTCs, yet they have disease specific problems and their intensive treatment regimens can produce substantial long-term side-effects<sup>41, 42</sup>. Thus, mechanisms for supporting cancer survivors may differ from LTCs where treatment is usually associated with health improvements<sup>43</sup>. This may negatively impact on cancer survivors' self-efficacy to self-manage, regardless of the social support offered<sup>44</sup>. This article, therefore, makes an original contribution to the cancer nursing literature by (a) identifying, from the survivor

perspective, changes experienced in cancer survivors' relationships with family and friends (b) the types of SM used by survivors to enhance their health and well-being in the face of a major life event, and (c) the links they perceive between social support and SM. While some relationship changes documented in the article should seem familiar to cancer nurses, who hear aspects of their patients' stories on a daily basis, these stories have not previously been documented or analyzed systematically, nor developed into a coherent, evidence-based model. Finally, the article aims to link these findings to practical strategies for nurses to promote supported SM for cancer survivors.

## **Methods**

### **Study Design**

This qualitative, interview study was part of a sequential mixed methods study, made up of a survey and interviews, examining patterns of SM practices in cancer survivors over time, from pre-diagnosis, through treatment and into survivorship<sup>45-48</sup>. The survey found that types and patterns of SM practices (diet, exercise, complementary and alternative medicine (CAM), psychological therapies, spirituality/religion, support groups) altered over time, but were utilised most in survivorship<sup>45</sup>. The qualitative component found that the level and type of SM practice used were often influenced by the social support accessed<sup>47</sup>. Having drawn issues and concepts, relating to social support and SM use in chronic illness from the literature<sup>21, 40</sup>, we wanted to interrogate our dataset further to explore how cancer survivors' changing social relationships influenced their desire to self-manage. To do this, we employed a thematic analysis method<sup>49</sup>, which was suited to our theoretical framework for the analysis – the development of 'ideal types'

<sup>50</sup>, as it enabled us to code, then group together different types of relationships that participants described. We then worked with the dataset, to draw out any links between participants' social relationships, their perceived social support and health and lifestyle outlooks. We were interested in exploring why and how cancer survivors' social relationships might change over time, whether this influenced their ability to self-manage and their SM choices.

### **The development of ideal types: a theoretical framework**

Through building typologies or 'ideal types' - a methodology developed by Weber and Schultz <sup>50</sup> - we were able to identify to what extent participants' lived experiences fitted into social constructs relating to the restructuring of relationships post-cancer. Using 'ideal types' to guide and inform our data analysis process, we drew comparisons between the typologies, participants' experienced realities and their subsequent ability to self-manage in survivorship <sup>50</sup>. The typologies identified (continuation of positive existing relationships, improvement of existing relationships, strain on existing relationships, termination of negative relationships, formation of new relationships, failure to form or maintain relationships) are not intended to categorize participants exclusively into one typology. Rather, we recognize that cancer survivors may identify with a range of typologies, depending on the relationships they engage or disengage with, over time. However, the typologies allow us to develop understanding of changes to social relationships a cancer diagnosis can incur, its impact on peoples' outlooks and SM abilities.

### **Setting**

The study took place in a large teaching hospital in the West Midlands, United Kingdom. Ethical approval was sought and obtained from the local research ethics committee in February 2012 (Study protocol number RG\_11-175, REC reference 12/WM/0030).

### **Access, Recruitment, Sampling and Data Collection**

Four hundred and forty-five participants took part in the survey study<sup>45, 46</sup>. Access to the study population was gained through contacting relevant oncology consultants at the participating hospital. To be eligible, participants had to be free from metastatic disease/local recurrence at the study outset and had finished their active cancer treatment over one year previously<sup>45, 46</sup>.

We selected our qualitative interview sample from our survey population, using a purposive sampling strategy that considered cancer type, age, gender, ethnicity and SM patterns. Two hundred and fifty-four survey respondents were willing to be interviewed. Of these, participants were selected based on the quantitative data analysis findings, which showed trends in SM practice uptake over time<sup>45</sup>. Four people from each of the ten cancer types (breast, prostate, colorectal, lung, melanoma, head and neck, non-hodgkin's lymphoma, stomach, oesophageal and bladder) included in the study were selected. A variety of ages were also sampled, with 13-14 participants chosen from the following age-groups: 20-40, 41-60 and >60 years. The range in gender, ethnicity and religion sampled reflects the diversity within the city (Table 2).

In total, forty people participated in the interview study. A narrative, 'story-telling' approach to data collection was chosen as it provided insights as to how people make sense of their behaviors in relation to other aspects and experiences in their lives, something that is essential to understanding the variation in health behaviors that we had observed in the quantitative analysis

among different population groups<sup>45, 46</sup>. Narrative approaches to research are largely interpretive in nature, involving multiple subjective representations of reality, drawn together in the analysis to explore the social and cultural influences shaping people's recollections and experiences. Use of a narrative approach enabled participants to talk openly about their cancer experiences, relationships, SM use and social support, enabling us to interpret the narratives from the stories provided. A topic guide informed the interview process and included questions such as '*Can you describe the reactions of your friends and family to your cancer diagnosis?*' and '*Can you tell me about the reasons for starting/stopping [certain] SM practices?*'

### **Data Analysis**

All 40 interviews were digitally recorded and transcribed. We took a narrative approach to analyzing the interview transcripts<sup>51</sup>, examining each one to see how, if at all, individuals' social relationships had changed over time. Throughout, we separated social support into family and friends, to see if these personal relationships, in particular, aided cancer survivors' recovery. Once these social support types had been identified, we inputted them into a working analytical framework. Throughout the thematic analysis process, we drew inspiration from some of the methodological work around grounded theory<sup>52</sup>, taking an iterative approach by moving back and forth between data and theory. We regularly undertook memo writing at different stages of the analysis to explore aspects of the data and discussed these in team meetings. We used the constant comparative method<sup>52</sup>, to establish any existing similarities and differences between participants' social support, relationships over time and SM use. Transcript data were inserted into a Framework matrix to enable data ordering and synthesis, whilst retaining the meaning and feeling of the interviewees' words<sup>53</sup>. This meant we could easily compare and contrast the data

across and within cases, to pull out relevant themes relating to social support, relationships and SM use. It also made the dataset more manageable and auditable <sup>49</sup>, while illuminating relationships that existed between the different categories.

This process enabled us to identify which participants held positive or negative outlooks post-cancer. We considered participants to have positive outlooks if they spoke of enjoying and appreciating the present, embracing the future and acknowledging good things arising from their cancer diagnosis. In contrast, we considered participants to have negative outlooks if they spoke of having little or no hope, not looking to the future or having poor quality of life post-cancer.

As we analyzed the data thematically, it became clear that participants' outlooks and SM use were linked to the social relationships they had formed, or lost. Through studying the transcript data, alongside the existing literature on social support in chronic illness <sup>8-10, 17-21, 35, 40</sup>, we developed themes based around social support, the formation, maintenance and termination of personal relationships and perceived ability to cope in cancer survivorship. This enabled us to identify typologies of how cancer survivors restructure social relationships with family and friends (Table 1). Our analysis then considered how this influenced their use of SM practices.

## **Findings**

The data revealed strong links between the support participants received from families and friends and their outlook post-cancer.

## **Demographics of Participants**

The demographic variation between interview participants was diverse; ages ranged from 36 - 82 years, with a mean age of 61 years. Participants' ethnicities were White (n=28), Black (n=7) and South Asian (n=5) and 22 women and 18 men were sampled. A range of religions including Christian (n=23), Muslim (n=2), Sikh (n=2), Hindu (n=1), Jewish (n=1), Buddhist (n=1) and no religion (n=10) were identified. Table 2 details how these participant demographics aligned with the six typologies. Another key aspect of data variation was age: more young participants (mean: 51.7 years) described forming new relationships post-cancer, whilst older participants (mean: 61.4 years) described continuing positive relationships. This corresponds with the survey findings, which found younger people sought more new methods of social support through attending support groups, or utilising interactive psychological and CAM therapies<sup>45</sup>.

## **Typologies of Restructuring Relationships with Friends and Family**

### **The Continuation of Positive Existing Relationships**

Most participants in our study held positive outlooks about their health and lifestyles post-cancer, feeling lucky to have survived, vocalizing gratitude and how they had their family and friends to live for. SM practices such as group prayer, or support group attendance, often reflected this social interaction, containing supportive elements within them.

*'I [have always] talk[ed] to everybody in church...They pray for me...If they don't see me come to church...[They are] wondering 'what happened?' When I go to church and they pray for you and the pastor preaches to you, you feel so happy...It's like you're into a different world.'*(SS1652)

All participants who reported receiving consistently good support from family and friends had positive mental outlooks regarding their life post-cancer. The ability to put things into perspective and see the bigger picture often influenced their SM choices, with activities such as gardening, Reiki and meditation all being cited as raising self-awareness.

*'I love [gardening], whereas at one time I wasn't that bothered...You suddenly realize, you watch every little bud...that...starts sprouting up...Watching it grow and thinking oh this is what life's about. The birds become a lot more relevant, you can hear the noises...I'd say...To my daughter...'Just look at that tree there and all that blossom'...It changed my outlook. It's amazing what you can survive and what you can cope with when you have to.'* (SS1207)

Where cancer had brought family members closer; they were credited with providing emotional, informational, instrumental and appraisal support. This gave participants reassurance that they could cope with their cancer and spurred them on to engage with SM activities on a daily basis.

*'The support I get from my family encouraged me...They started giving me encouragement...So then I joined...a leisure club, so I'm doing light exercise. Walking, cycling, swimming.'* (SS1497)

Participants frequently identified children and grandchildren as their reason to be strong in survivorship and look to the future. Participants were often motivated by their offspring to stay strong and this tended to incorporate a SM component.

*'Since I retired [prior to cancer] I'm quite heavily involved with my grandchildren... We do quite a lot of swimming... We go to the local baths, we do long walks... Quite a bit of exercise... All of that has helped... I've been able to forget my problems and concentrate on others.'* (SS1943)

Some participants drew strength from friends' continued support and spoke of how they appreciated being treated as they had been prior to cancer. This was credited with helping many participants get through treatment and emerge stronger post-cancer. Support group attendance and group therapies were recognised as good mechanisms for coping with treatment side-effects.

*'If I hadn't had friends I'd have been struggling... I've had terrific support... Out in my social life... Which has helped me be the person that I am today... After I'd had my treatment, I came for the... Look Good, Feel Good, the sort of beauty one, which was lovely to go to.'* (SS1205)

### **The Improvement of Existing Relationships**

For some participants, living through cancer reasserted the emotional value they placed in people central to their lives. One participant described how her cancer experience had revalidated her relationship, resurrecting her marriage as a result.

*'We'd been separated about eight... months and... I said I've got a lump... He said I'll take you to the doctors... A year after my cancer treatment I said look we've had enough rubbish... Shall we get married again... That sort of marked the end of the – the year of treatment.'* (SS1207)

One woman spoke of talking more openly with her ex-husband since her cancer diagnosis, as he had also been diagnosed with cancer, so they shared details of each other's illnesses and provided reciprocal SM support about herbal remedies and dietary modifications.

*'My husband and I had been separated for two years, when we were actually both diagnosed with cancer...We began to talk more...Exchange information about anything...Or his concerns...I shall send him the information about... What I have here [herbal remedy].'* (SS1674)

### **Strain on Existing Relationships**

Some participants described how their relationships were negatively affected by cancer and guilt that their partner was taking on increasing care-giving roles, stopping the partner from having their own lives. For these people psychological therapies, such as counselling, often provided an outlet to express worries and fears they didn't feel it was fair to place on family members.

*'She wants to get out a bit more...I think she's fed up of coming with me to the hospitals...I don't blame her... I'm going for some well-being counselling...I never had any - any counselling like this before...The small things were getting - you know all these pressures...'* (SS1772)

For others, the apparent lack of emotional support received from their partners led to feelings of isolation and resentment. Though participants sometimes acknowledged this was their partner's way of coping, by separating themselves from cancer, this could create distance in their relationship. One woman spoke of how she might have benefited from some counselling as an outlet to talk things through, though this was never offered, indicating a missed care opportunity.

*'I was able to talk to my husband about [my cancer, but now he] ...blocks it out...assumes it's never going to come back ...I think it's more just a man thing of just not facing things...[Counselling] wasn't offered, and I never really thought to ask...It might have been helpful...So, no, I haven't had anything like that.'* (SS1687)

### **The Formation of New Relationships**

Some participants described how cancer had led to the formation of new relationships with other cancer survivors, as they bonded emotionally through shared illness experiences. These participants often found support groups beneficial for sharing stories and helping to manage emotional issues. However, some participants had been unaware of the existence of relevant support groups whilst undergoing treatment and felt this may have slowed down their recovery.

*'Having my friend, who has gone through cancer...I'm able to reflect with her...And now she helps me... Which is brilliant...If...I'd been given, not a buddy, but...some people to hook into...I may have got to the point I am now a couple of years ago.'* (SS1178)

A couple of participants spoke of finding it easier to maintain relationships with people they had not known before cancer. They felt that they were not being compared to their former selves, but were seen in their own right, without the shadow of cancer altering people's perceptions of them. Often, they had altered their SM activities to reflect these newly formed relationships.

*'We bought a caravan in Paignton, and I've met friends there. They phone me up...Not to see how I am because of my illness, just how I am... [My] quality of life now is fantastic... We can be down there...Going up on Dartmoor... We're on Dartmoor within 10 minutes.'* (SS1788)

### **The Termination of Negative Relationships**

Many participants spoke of how some friends had distanced themselves, emotionally and practically, since their cancer diagnosis, not getting in touch or discussing their illness with them.

*'Some friends did have difficulty with it. There was one particular...couple that lived by us that were very, very friendly with us...He never spoke to me for two years. He didn't know what to say. He used to cross the road ...Anyway that was that.'* (SS1025)

This participant described how, despite the deterioration of these friendships, he remained focused on recovering from cancer, by pursuing lifestyle goals and activities.

*'You've got to be positive about wanting to recover...I used to walk every day and first day I got to the bottom of my drive and then back in. A week later I got to my next door neighbour's drive and back...And just slowly pushed it and pushed it and pushed it and pushed it.'* (SS1025)

While some participants acknowledged that their friends distanced themselves as a coping mechanism, others felt ostracized and stigmatized by them, making them realize who their true friends were. Though these participants' social activities were limited due to feeling excluded, they were able to reduce feelings of anxiety by taking comfort and finding a new sense of self in more solitary therapeutic activities such as walking, swimming, cycling, tai-chi and yoga.

*'When I had cancer there was a few people...that I thought would ring me...and didn't. That's upsetting...I have really nothing to do with [those] people. It has made me a bit stronger – you see that other people wouldn't be bothered whether you were dead and you think, 'Well, sod them'. I can find [walking] therapeutic 'cause I can get anxious...I just find it helps.'* (SS1892)

For a few participants, the strain of cancer forced them to reassess the validity of their personal relationships. One participant described how the emotional uncertainty she was facing led her to admit that her relationship with her partner should end, despite his efforts to provide SM support.

*'I was with somebody...I mean, he was trying to help me...He...went out and bought lots of vitamins and everything else...But...when I was diagnosed with the cancer...I realized...he wasn't for me...You're supposed to be feeling that secure feeling, and I wasn't. I was feeling very vulnerable... ..I couldn't see my future with him.'* (SS1608)

### **The Failure to Form or Maintain Relationships**

A few participants described weak or absent social networks and displayed more negative outlooks, feeling they were in a bad place physically or mentally post-cancer and that many good things had vanished from their lives. One man with severe treatment side-effects rarely saw his friends or left the house anymore, diminishing his engagement with any sorts of SM activities.

*'I was always happy go lucky and...thought I wouldn't retire I would just keep on going...Be in good health...and retire about probably 70, around about that. Now I have no future, I don't know whether I'm going to go tomorrow...that's it...Every day is a different day.'* (SS1004)

A couple of participants spoke of receiving little to no support from friends or family, while others had received good support from either their partner or family, but little or no support from other social relationships. This led to feeling less inclined to engage with SM behaviors.

*'The family's non-existent really... I'm on my own a lot...She [sister] never came to see me when I'd had that cancer...Me Dad says, "Oh [she] might be in." She never got in touch, which I found despicable...I haven't looked after myself because I haven't had the energy.'* (SS1892)

Some participants spoke of their children lacking in support since their cancer diagnosis, sometimes for practical reasons, such as living far away and being unable to visit much. However, a few perceived more widespread lack of support, noting that their children didn't invest time in them, whether on a practical, informational, appraisal or emotional level. These participants tended to lack motivation to engage with dietary, exercise or CAM therapies, instead drawing comparisons between what they had done in the past, but were limited by in the present.

*'My children have all grown up and gone...They don't even come back or phone me and ask me how I am...I've put a lot of weight on now due to the steroids, I think being unemployed and being active before...This is you know...I was quite fit before, and quite active like.'* (SS1772)

For a couple of participants, cancer had enforced social changes which magnified their daily isolation. This was largely due to physical side-effects from treatment, which meant they were unable to socialize with friends or engage with SM practices that required group interaction.

*'Before I probably would have went dancing with you, I'm telling you, I was...I had a great life...[Now] I don't go out...What can I do if I go out?...I can't drink, I can't eat...A lot of people won't eat or drink in front of me because they know that I can't eat or drink.'* (SS1004)

## **Discussion**

The interview findings provide insights into how changing relationships experienced by cancer survivors before, during and after cancer can impact their outlook to their health and well-being, shaping the way they reconcile their cancer experience within their wider life context. Using Weber's 'ideal type' construct<sup>50</sup> as a framework for our own analysis, we identified how participants' changing social relationships influenced their ability to self-manage in survivorship (Table 1). Participants who maintained good relationships over time retained positive outlooks, highlighting the benefits of social support in survivorship. These findings support the relevance of the PRISM framework<sup>23</sup>, which suggests that support from friends and family may allow cancer survivors to self-manage more easily, due to a desire to achieve their future goals through the optimization of their health. Similarly, those with weak, or absent, social support structures, may be less likely to engage with health promoting SM activities, due to feelings of decreased self-efficacy in their ability to do so<sup>38,44</sup>. Thus, the iterative relationship between evolving social relationships and SM can be better understood. Social support can enhance cancer survivors' capacity for SM, which may further boost social interactions and self-efficacy and lead to greater levels of support being received. This is important for nurses and policy makers to consider when thinking about which SM practices to recommend to cancer survivors, as SM practices

with high levels of social interaction, such as support groups or group therapies, may have particular benefits for health and well-being, and may be more likely to be sustained long term.

However, our findings go further to suggest that even when there is strain or termination of relationships, there may be opportunities for SM that do not rely on the maintenance of pre-cancer social networks. For a few, ending relationships invoked a resilience and determination to get on with life, as they felt they knew their true friends. This suggests that while a loss of social support can negatively impact and increase feelings of isolation, it can also help cancer survivors reassess the importance and meaningfulness of their relationships and values that have altered over time. This may explain why a few participants spoke of finding it easier to be friends with people they had met post cancer, by investing in relationships that reflected their current values and priorities. This suggests the value of making available opportunities for cancer patients and survivors to be able to meet with and offer support to one another.

The finding that some participants formed new relationships with other cancer survivors is unsurprising. Peers can provide emotional, practical, appraisal and informational support through the perspective of shared personal experience and connectedness<sup>54, 55</sup>; this is often missing from relationships with friends and family<sup>56</sup>. The strain that cancer can place on close social networks means cancer survivors may turn to more outward facing networks<sup>6</sup>, using them as a SM tool for initiating lifestyle changes. Factors such as cancer survivors' personal characteristics, cancer type and stage, treatment side-effects, the emergence of carer and caregiving roles<sup>6</sup>, the desire to

return to normality<sup>57</sup> and their perceived need for support<sup>58</sup>, may influence to what extent cancer survivors are willing and able to revalidate or relinquish certain relationships, or start new ones.

The findings illustrate that, for some, cancer can inhibit the formation or maintenance of relationships, due to diminished confidence in social interactions, with debilitating effects on social relationships, self-efficacy and subsequent SM behaviors. Increased clinical support from nurses can address this, through exploring survivors' support networks and preferred SM practices, then using tailored SM plans to guide cancer survivors to try things they had not previously considered that might enhance physical, social and emotional well-being. This may be through signposting a cancer survivor, who lives alone and suffers with weakness and fatigue, to a walking club to increase their fitness and strength, while facilitating social interaction. Similarly, a cancer survivor with depression and anxiety may benefit from cognitive behavioral therapy, alongside support group attendance where they can discuss their worries and concerns.

Nurses can encourage interventions combining social support components<sup>23</sup> with realistic strategies for health and are ideally placed to do so, being at the forefront of patient care and primed to assess patient needs. When identifying suitable SM practices, nurses should also assess patients' social support, which may impact on the suitability and nature of the SM practice. This has policy implications, with integrated care services that promote shared decision-making, optimise individual health and support people with LTCs to manage their condition, being increasingly promoted by policy-makers<sup>30, 31, 59</sup>. The introduction of NHS personalised health budgets<sup>32</sup> aims to increase the personalisation and precision of care for people with LTCs,

helping them to manage and support their own health. Individuals require different strategies to manage their condition and holistic need assessments should identify the information, support and follow-up care required. A tailored care plan, specific to individual needs and abilities<sup>59</sup> may help address the gaps in social support experienced by many cancer survivors.

## **Conclusion**

This article has examined the social support and changing relationships experienced by cancer survivors over time and its influence on their SM engagement. It has added two empirical contributions to the literature: that relationships are significantly affected by the cancer experience and that these changing social relationships have varying impact on the way survivors self-manage their health. The rigorous empirical research used in the study, including the high quality sample, allows us to make analytic generalizations to a wider population of cancer survivors, both at a national and international level, although further empirical work is required to support this. The findings are significant in the field of nursing scholarship because the type of theoretical approach that we used can be utilized in practice by nurses to explore with their patients which relationship changes they are going through, rather than making assumptions about the support received from family and friends. The typologies can provide a framework for patient-centred discussions with survivors and co-production of SM plans.

Nurses and policy makers need to think strategically about how to provide SM support to cancer survivors. In addition to providing tools with which to enhance nurses' communication skills with patients, this article has offered support for nurses to provide best patient care, by offering

practical suggestions for SM that might support people with different relationship types and support networks. Appropriate clinical processes and interventions are needed which are responsive to the support individual cancer survivors require. This is particularly important for Primary Care nurses who care for cancer survivors making the transition from patient to survivor and need to be equipped with skills to assess and guide them. Nurses may become part of the picture of social support that enables patients to make the best choices available, by using SM strategies to engage in health giving lifestyle practices<sup>60, 61</sup>.

## References

1. Cohen S. Social Relationships and Health. **American Psychologist** 2004;59(8):676-684.
2. Greenglass ER. The contribution of social support to coping strategies. **Applied Psychology: An International Review. Special Issue on Women and Management**. 1993;42:323-340.
3. Marshall NL, Barnett RC. Work related support among women in care-giving occupations. **Journal of Community Psychology**. 1992;20:36-42.
4. Russell DW, Altmaier E, Van Velzen D. Job related stress, social support, and burnout among classroom teachers. **Journal of Applied Psychology**. 1987;72:269-274.
5. Cohen S, Syme S.L, eds. *Social Support and Health*. San Fransisco: Academic Press; 1985. Cohen S, Syme S.L, eds. *Issues in the Study and Application of Social Support*.
6. Schafer MH, Koltai J. Cancer Diagnosis and Mental Health among Older White Adults: Moderating Role for Social Networks? **Society and Mental Health**. 2015;5(3):182-202.
7. Baum A, Taylor S.E, Singer J.E, eds. *Handbook of Psychology and Health*. NJ: Hillsdale; 1984. Cohen S, G M, eds. *Social Support, Stress and Buffering Hypothesis: A Theoretical Analysis*.
8. Tillotson L.M, Smith M.S. Locus of control, social support, and adherence to the diabetes regimen. **Diabetes Educ**. 1996;22:133-139.
9. Ruggiero L, Spirito A, Bond A, Coustan D, McGarvey S. Impact of social support and stress compliance in women with gestational diabetes. **Diabetes Care**. 1990;13:441-443.
10. Fallowfield L, Hall A, Maguire G, et al. Psychological Outcomes of Different Treatment Policies in Women with Early Breast Cancer Outside a Clinical Trial. . **BMJ**. 1990;310(575-80).
11. Samarel N, Fawcett J, Tulman L. Effect of Support Groups with Coaching on Adaptation to Early Stage Breast Cancer. **Nursing and Health**. 1997;20:15-26.
12. Huang S-M, Lee C-H, Chien L-Y, Liu H-E, Tai C-J. Issues and Innovations in Nursing Practice. Postoperative quality of life among patients with thyroid cancer. **JAN**. 2004;47(5):492-499.
13. Berkman LF, Glass T, Brissette I, Seeman TE. From social integration to health: Durkheim in the new millenium. **Social Science and Medicine**. 2000;51(6):843-857.
14. Greenglass ER, Fiksenbaum L, Burke RJ. Componemts of social support, buffering effects and burnout: Implications for psychological functioning. **Anxiety, Stress and Coping**. 1996;9:185-197.
15. Langford CPH, Bowsher J, Maloney JP, Lillis JP. Social support: a conceptual analysis. **Journal of Advanced Nursing**. 1997;25(1):95-100.
16. Helgeson VS, Cohen S. Social support and adjustment to cancer: Reconciling descriptive, correlational, and intervention research. . **Health Psychology**. 1996;15(2):135-148.
17. Usta Y. Importance of Social Support in Cancer Patients. **Asian Pacific J Cancer Prev**. 2012;13:3569-3572.
18. Samarel N, Fawcett J, Tulman L. Effect of Support Groups with Coaching on Adaptation to Early Stage Breast Cancer. **Nursing and Health** 1997;20:15-26.
19. Ong L, Visser M, Lammes F, et al. Doctor-Patient Communication and Cancer Patients' Quality of Life and Satisfaction. **Patient Educ Couns**. 2000;41:145-156.
20. Vogel B, Leonhart R, Helmes A. Communication Matters: The Impact of Communication and Participation in Decision Making on Breast Cancer Patients' Depression and Quality of Life. . **Patient Educ Couns**. 2009;77:391-397.
21. Bandura A. Health promotion from the perspective of social cognitive theory. **Psychology and Health**. 1998;13(4):623-649.
22. Hibbard J, Gilbert H. *Supporting people to manage their health: an introduction to patient activation*. London: The King's Fund; 2014.

23. Pearce G, Parke HL, Pinnock H, et al. The PRISMS taxonomy of self-management support: derivation of a novel taxonomy and initial testing of its utility. **Journal of Health Services Research and Policy**. 2016;21(2):73-82.
24. Findley P, Sambamoorthi U. Preventive Health Services and Lifestyle Practices in Cancer Survivors: A Population Health Investigation. **J Cancer Surviv**. 2009;3:43-58.
25. Boon H, Olatunde F, Zick S. Trends in Complementary/Alternative Medicine Use by Breast Cancer Survivors: Comparing Survey Data from 1998 and 2005. **BMC Women's Health**. 2007;7(4).
26. Sirois F, Gick M. An Investigation of the Health Beliefs and Motivations of Complementary Medicine Clients. **Social Science and Medicine**. 2002;55:1025-1037.
27. Smithson J, Paterson C, Britten N, Evans M, Lewith G. Cancer Patients' Experiences of Using Complementary Therapies: Polarization and Integration. **Journal of Health Services Research Policy**. 2010;15(2):54-61.
28. Tovey P, Broom A. Oncologists' and Specialist Cancer Nurses' Approaches to Complementary and Alternative Medicine and Their Impact on Patient Action. **Social Science & Medicine** 2007;64(12):2550-2564.
29. Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie B. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. **The Lancet**. 2012;380(9836):37-43.
30. The King's Fund. Integrated Care. London. Available at: <https://www.kingsfund.org.uk/topics/integrated-care>. Accessed 23.01.2017, 2017.
31. Excellence NfHaC. *Multimorbidity: Clinical Assessment and Management*. London: NICE; 2016.
32. England N. Personal Health Budgets. NHS. Available at: <https://www.england.nhs.uk/healthbudgets/>. Accessed 23.01.17, 2017.
33. Berkman L.F, T G, eds. *Social Integration, social networks, and health*. New York: Oxford University Press; 2000. L.F. B, I K, eds. *Social Epidemiology*.
34. Kaplan R.M, Toshima M.T. **The functional effects of social relationships on chronic illnesses and disability**. New York: John Wiley; 1990.
35. Glasgow R.E, Toobert D.J. Social environment and regimen adherence among Type II diabetic patients. **Diabetes Care**. 1988;11:377-386.
36. Levy R.L. Social support and compliance: A selective review and critique of treatment integrity and outcome measurement. **Soc Sci Med**. 1983;17:1329-1338.
37. Wortman C.B, Conway T.L, eds. *The role of social support in adaptation and recovery from physical illness*. Orlando, FL: Academic Press; 1985. Cohen S, S.L S, eds. *Social Support and Health*.
38. Foster C, Breckons M, Cotterell P, et al. Cancer survivors' self-efficacy to self-manage in the year following primary treatment. **J Cancer Surviv**. 2015;9:11-19.
39. Clark NM, Becker MH, Janz NK, Lorig K, Rakowski W, Anderson L. Self-management of Chronic Disease by Older Adults. **Journal of Aging and Health**. 1991;3:3-27.
40. Gallant M. The Influence of Social Support on Chronic Illness Self-Management: A Review and Directions for Research. **Health Education and Behaviour**. 2003;30(2):170-195.
41. Sitzia J, Hughes J, Sobrido L. A Study of Patients' Experiences of Side-Effects Associated with Chemotherapy: Pilot Stage Report. **Int. J. Nurs. Stud**. . 1995;32(6):580-600.
42. Macmillan. Side Effects of Cancer Treatment. **Macmillan Cancer Support**. Available at: <http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Gettingtreatment/Makingtreatmentdecisions/Sideeffectsoftreatment.aspx>. Accessed 19/03/2014, 2014.
43. Disease TCfMC. What is Chronic Disease? **University of Michigan**. Available at: <http://cmcd.sph.umich.edu/what-is-chronic-disease.html>. Accessed 19/03/2014, 2014.

44. Paterson C, Robertson A, Nabi G. Exploring prostate cancer survivors' self-management behaviours and examining the mechanism effect that links coping and social support to health-related quality of life, anxiety and depression: A prospective longitudinal study. **European Journal of Oncology Nursing**. 2015;19:120-128.
45. Shneerson C, Taskila T, Holder R, et al. Patterns of self-management practices undertaken by cancer survivors: variations in demographic factors. **European Journal of Cancer Care**. 2015;24(5):683-694.
46. Shneerson C, Taskila T, Greenfield S, Gale N. A survey investigating the associations between self-management practices and quality of life in cancer survivors. **Supportive Care in Cancer**. 2015;23(9):2655-2662.
47. Henshall C, Greenfield S, Gale N. The role of self-management practices as mechanisms for re-establishing normality in cancer survivors. **Qual Health Res**. 2016.
48. Shneerson C, Gale N. Using mixed methods to identify and answer clinically relevant research questions. **Qualitative Health Research**. 2015;25(6):845-856.
49. Ritchie J, Lewis J. **Qualitative Research Practice: A Guide for Social Science Students and Researchers**. London: Sage Publications; 2003.
50. Psathas G. The Ideal Type in Weber and Schutz. In: Endress M, Psathas G, Hishashi N, eds. *Explorations of the Life World Continuing Dialogues With Alfred Schutz: Contributions to Phenomenology*. Netherlands: Springer; 2010.
51. Mattingly C, Garro L, eds. *Narrative as Construct and Construction*. London.: University of California Press Ltd.; 2000. Mattingly C, Garro L, eds. *Narrative and the Cultural Construction of Illness and Healing*.
52. Bryman A. **Social Research Methods**. 3rd ed. Oxford: Oxford University Press; 2008.
53. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. **BMC Medical Research Methodology**. 2013;13(117).
54. Dunn J, Steginga S, Rosoman N, Millichap D. A Review of Peer Support in the Context of Cancer. **Journal of Psychosocial Oncology**. 2003;21(2):55-67.
55. Treanor C, Donnelly M. Late effects of cancer and cancer treatment—the perspective of the patient. **Support Care Cancer**. 2016;24:337-346.
56. Ussher J, Kirstena L, Butowb P, Sandovala M. What do Cancer Support Groups Provide Which Other Supportive Relationships Do Not? The Experience of Peer Support Groups for People with Cancer. **Soc. Sci. and Med**. 2006;62(10):2565-2576.
57. Henshall C, Greenfield S, Gale N. The role of self-management practices as mechanisms for re-establishing normality in cancer survivors. **Qualitative Health Research**. 2016:1-14.
58. Jansen F, van Uden-Kraan CF, van Zwieten V, Witte BI, Verdonck-de Leeuw IM. Cancer survivors' perceived need for supportive care and their attitude towards self-management and eHealth. **Support Care Cancer**. 2015;23:1679-1688.
59. DOH. *Living With Long Term Conditions: A Policy Framework*. London DOH; 2012.
60. Support MC. National Cancer Survivorship Initiative. **Macmillan Cancer Support** 25/08/2011. Available at: <http://www.ncsi.org.uk/>. Accessed 17/10/11, 2011.
61. Gao W, Yuan C. Self-Management Programme for Cancer Patients: A Literature Review. **International Nursing Review**. 2011;58:288-295.

**Table 1: Typologies of How Cancer Survivors' Restructure Social Relationships with Family and Friends Following a Cancer Diagnosis: Perspectives of Interview Participants**

Continuation of Positive Existing Relationships	Improvement of Existing Relationships	Strain on Existing Relationships	Termination of Negative Relationships	Formation of New Relationships	Failure to Form or Maintain Relationships
<ul style="list-style-type: none"> <li>• Cancer reaffirms importance and strength of relationship</li> <li>• Consistent and increased emotional, practical and informational support provided</li> <li>• 'Close knit' relationships maintained</li> <li>• Draw strength from relationships, enabling an ability to look to the future</li> <li>• Treated the 'same as before cancer'</li> <li>• Ability to maintain social life and engage in self-management activities</li> </ul>	<ul style="list-style-type: none"> <li>• Reassessment of priorities and values</li> <li>• Increased emotional, practical and informational support provided</li> <li>• Provision of support that was absent prior to cancer</li> <li>• Enforced changes to social life impact on relationships</li> <li>• Increased ability to talk more openly</li> </ul>	<ul style="list-style-type: none"> <li>• Emergence of carer/caregiver roles and guilt at being a burden</li> <li>• Enforced changes to social life impact on relationships</li> <li>• Distancing of friends and family due to lack of emotional support and failure to acknowledge cancer</li> </ul>	<ul style="list-style-type: none"> <li>• Acknowledgment of decreased validity and meaningfulness of relationship</li> <li>• Distancing of friends and family due to lack of emotional support and failure to acknowledge cancer</li> <li>• Reassessment of priorities and values</li> <li>• Flaws and weaknesses of relationship clarified</li> <li>• Clarification of what is wanted from relationship</li> <li>• Resilience and determination to 'get on with life'</li> </ul>	<ul style="list-style-type: none"> <li>• Seeking of peer support (one to one or through support groups)</li> <li>• Desire to share experiences with others with cancer</li> <li>• Lack of comparisons made to pre-cancer self</li> <li>• Reassessment of priorities and values post-cancer</li> <li>• Recognition of need for emotional support</li> </ul>	<ul style="list-style-type: none"> <li>• Diminished confidence in mind and body</li> <li>• Sense of increased vulnerability, decreased self-esteem and lack of hope</li> <li>• Increased social isolation and decreased self-management uptake due to physical limitations</li> <li>• Absence of practical, emotional or informational support</li> <li>• Wary of entering relationships as cancer seen as a deterrent and burden to others</li> </ul>

Table 2: Demographic Characteristics of Participants and their Associated Typologies

Typologies <sup>a</sup>		Continuation of Positive Existing Relationships (n=25)	Improvement of Existing Relationships (n=11)	Strain on Existing Relationships (n=16)	Termination of Negative Relationships (n=4)	Formation of New Relationships (n=3)	Failure to Form or Maintain Relationships (n=3)
Average Age (years)		61.4	55.2	60.6	57.5	51.7	55.7
Ethnicity (n (%))	White	18 (72)	8 (73)	13 (81)	3 (75)	3 (100)	2 (67)
	Black	20 (80)	1 (9)	2 (13)	1 (25)	0 (0)	1 (33)
	South Asian	2 (8)	2 (18)	1 (6)	0 (0)	0 (0)	0 (0)
Gender (%)	Women	13 (52)	10 (91)	9 (56)	1 (25)	1 (33)	1 (33)
	Men	12 (48)	1 (9)	7 (44)	3 (75)	2 (67)	2 (67)
Religious (%)	Yes	17 (68)	9 (82)	12 (75)	3 (75)	3 (100)	2 (67)
	No	8 (32)	2 (18)	4 (25)	1 (25)	0 (0)	1 (33)

<sup>a</sup>Numbers add up to more than 40 as some participants expressed elements of more than one typology