



Cancer, Relationships & Counselling

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March 2021



About us

We Hear You (WHY) provides emotional support through free, professional counselling services for anyone who has been affected by cancer or other life-threatening conditions. We support children, young people and adults across Bath and North East Somerset, Somerset and Wiltshire.

This data in this report was collected and analysed by Dr Olly Clabburn, a researcher from the Wellcome Centre of Cultures and Environments of Health at the University of Exeter, in collaboration with We Hear You.

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Published by: We Hear You, Frome Town Hall

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Registered charity number: 1156001

Publication date: March 2021

Acknowledgements

We'd like to thank all those who took the time to speak to us about their experiences and its impact on their relationships: without your input this report would not have been possible.

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Foreword



WHY have supported many couples impacted by cancer over the last 26 years. We know only too well how the condition has a ripple effect across family and friendship networks.

In 2019 we were delighted to begin a collaborative project for our first piece of research with The Wellcome Centre for Cultures and Environments of Health, at the University of Exeter to look in more detail at the impact cancer has on relationships and on those that support cancer patients by providing counselling.

This report contains five clear recommendations around the provision of mental health support for those impacted by cancer. It calls for psychological support to be part of the holistic cancer care experience which is provided; particularly as so many of the people we spoke to said that the emotional aspects of cancer were as challenging to deal with as the physical aspects. It also calls for counselling to be a core part of cancer care, recognising that more resources will be needed to support community organisations in order to minimise waiting times. The report recognises that there is not a 'one size fits all' model, each person's needs will differ slightly and offering a range of therapeutic support tools is vital. Valuing the importance of relationships is also something that is often overlooked. More recognition for the impact on partners is required and support in nurturing these couple relationships during a cancer experience is suggested as a good support network can improve health outcomes.

WHY will continue to champion the importance of counselling and campaign for this to be delivered routinely as part of holistic cancer care. In addition, we will evaluate the work we carry out as a charity and look for additional areas of research that we would like to explore. This will strengthen our service and help us to deliver the best care possible to our clients and their families.

Anne Montague, Chair and Melissa Hillier, Director

Summary of key findings

The impact of cancer on relationships

All participants described how cancer can impact upon adult relationships. Whether the participant was a person living with and beyond cancer, a partner of someone living with cancer, cancer has the potential to affect relationships in a plethora of ways.

Communication within the relationship

All participants discussed the impact of cancer on communication within a close relationship. A diagnosis also has the potential to highlight communication incompatibilities within the relationship. Oftentimes these already existed for couples, yet cancer brought them into realisation. In contrast, we also found that cancer has the potential to bring couples closer together through enhanced communication. Counselling enables people to explore and understand where difficulties may lie in their relationship.

Intimacy and the physical relationship

71% of survey respondents said that intimacy and their physical relationship had been 'greatly affected' or 'affected' by cancer. This finding was similarly reinforced through the interview data collected with people living with and beyond cancer, their partners, and cancer counsellors.

Counselling in the field of cancer

Many people living with and beyond cancer considered specialist counselling to be as life-saving as clinical treatments and procedures. The therapeutic space endorses holistic cancer care whereby clients can explore the issues which matter most to them. It was also considered an impartial space to vent frustrations, explore thoughts and feelings which have been hidden from their partner, and to better understand how previous life traumas/experiences may contribute to their understanding of how cancer has impacted their relationship.

Cancer counsellors

The warmth, empathy and highly skilled nature of counsellors supported clients to feel able to reassess their lives and offered people space and a chance to explore how their life (and relationship) has changed as a result of cancer. This exploration allows people living with and beyond cancer to rebuild lives.

Where next?

Recommendations for cancer counselling services

1 Promote and campaign the importance of holistic cancer care* with specific focus on the mental health and wellbeing for people living with and beyond cancer, and their partners.

As a charity with expertise in cancer counselling, WHY is ideally placed to increase awareness amongst policy makers, commissioners, clinicians and funders about the importance and need for holistic cancer care provision, including therapeutic support, those interviewed for this research were keen to see the charity take on this role.

2 Counselling to be a standard aspect of cancer care which is available alongside NHS clinical pathways (i.e. aligned with NHS treatment).

Counselling was identified as a crucial way to help people cope with cancer and the consequences of having the disease. It was strongly felt by participants in this research that psychological support should be a standard aspect of cancer care provided by the NHS.

3 Recognising that relationships are a key source of support for people living with and beyond cancer and their partners. Ensuring appropriate support is available for couples to nurture/maintain their relationship.

Cancer does not take place in a vacuum of our lives. Instead, the effects of cancer ripple outwards and have a significant impact on partners of people affected by the disease. It is vital to acknowledge cancer as a 'we disease' and therefore provide support for people who are caring for individuals affected by cancer.

*Holistic cancer care: integrating both conventional (medical/clinical) and complementary approaches to cancer care. This encourages a focus on the 'whole' person and recognises the importance of emotional, social, spiritual, lifestyle and relationships all contributing to optimal care (Cadet et al., 2016).

Where next?

Recommendations for cancer counselling services

4

Resources for counselling services to reduce waiting times, increase counselling availability, expand reach and promote accessibility.

With the number of people affected by cancer due to increase from 2.9m to 5.3m in the next 20 years (Maddams et al., 2012) and with more than 50% of people living for more than 10 years after diagnosis (Cancer Research UK, 2018), it is vital that investment is directed towards community services which support patients and their families. The research findings in this report demonstrate the value that individuals with cancer and partners place on holistic care, and how counselling has supported them to manage, cope and better understand this life changing experience. At present, the majority of counselling services are carried out in the community by the third sector. Such services are therefore not funded by the NHS as standard cancer care. Instead, funding for these vital services is often by short term grants and donations which makes long term planning and delivery more challenging. Ensuring longer-term funding for these counselling services is key in providing optimal holistic cancer care for people living with cancer and their partners.

5

Continue expansion/growth of alternative counselling services (e.g. family days, outdoor and active sessions).

As WHY increases the range of services it provides, it can reach more diverse groups of people through providing additional services which appeal to individual preferences. As identified by our research, this should be actively encouraged to further expand our service provision and reach to improve the lives of local people affected by cancer.

About the project

First off, thank you for taking the time to find out about the project. The aim of this report is to provide an overview of the project, and importantly, present some of the key findings.

The project began in March 2020 with data collection finishing in October of the same year. It comprised of three data collection phases which are summarised on page 12 of this report.

This was a collaborative project between We Hear You (a cancer counselling charity based in Frome, Somerset), and the Wellcome Centre for Cultures and Environments of Health at the University of Exeter. Led by Dr Olly Clabburn, it was supported by colleagues Dr Charlotte Jones and Dr Felicity Thomas from the university, and Melissa Hillier, Director at We Hear You.

We hope that this report provides you with an insight to the project, and welcome any thoughts, comments or questions which you may have whilst reading.

“I felt listened to and understood. It felt like a safe place to unburden myself of all my pent up emotions which in turn helped me to reframe my approach to my partner and family.”
(Survey 12)

Aims

There were two overarching aims to the project with supporting objectives for each.

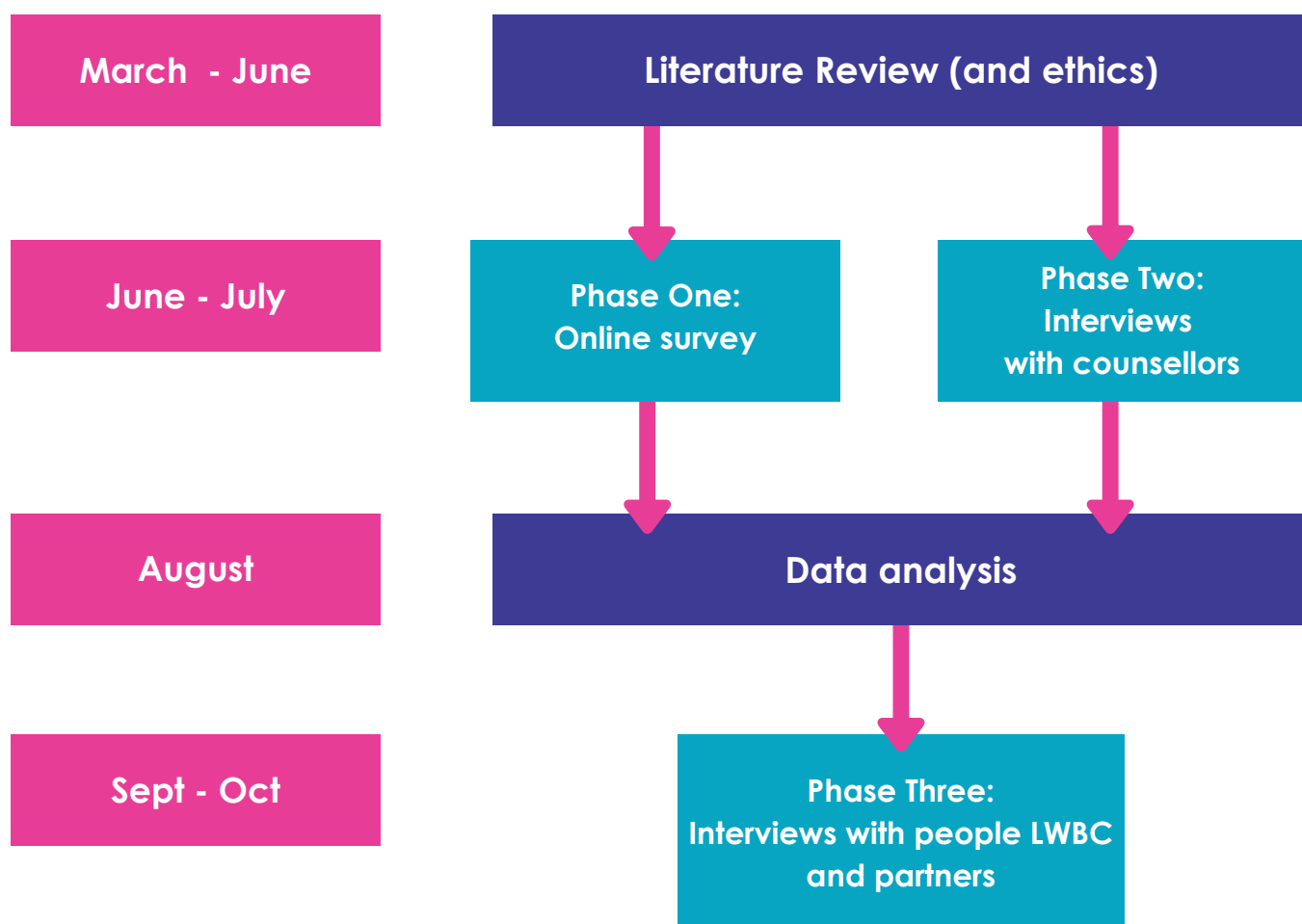
- 1) To investigate how cancer impacts adult relationships/couples
 - Explore how cancer impacts the individual lives of people living with and beyond cancer (LWBC) and the lives of their current/former partner's.
 - Explore how the shared relationship is impacted when one person is living with and beyond cancer.
- 2) To investigate counselling as a means of psychotherapeutic support for individual adult people LWBC, their partners, and for the shared relationship.
 - Identify counsellors' perceptions of the purpose/outcomes of counselling in the field of cancer
 - Identify clients' perceptions of the purpose/outcomes of counselling in the field of cancer.

Overview

An overview of the project timeline is presented below. The project began in March 2020 once ethical permissions had been obtained. A literature review was carried out to identify the key topics/issues which impact people LWBC and partners individually, but also, the shared relationship too. These topics then formed the basis of the questions for phase one and two (June-July).

Data analysis for the first two phases then informed the development of questions for the third phase of the project (interviews with people LWBC and current/former partners; September-October).

An advisory team meeting took place prior to each phase of data collection. This enabled screening of questions and discussion of additional areas for further exploration. To ensure a breadth of experience, this advisory team consisted of academics, WHY Trustees, clinical specialists, and former WHY clients.



Introduction

We began the project by carrying out a literature review. This was to investigate what was currently known about how cancer affects adult relationships/couples, and also, the impact of counselling as a psychotherapeutic means of support.

In total, seven databases were searched to identify literature. Hand-searching of related articles was also carried out. A summary of the key topics follows. The findings from the literature review informed the basis of questions for the online survey (phase one) and interviews with counsellors (phase two).



“ I needed to be able to talk about my grief at my changing body, my feelings of being out of control during the investigations and treatment, (something that is a real issue for me) and my fear of death and the future, to someone who just listened, rather than tried to make things right. (Survey #19) ”

How cancer impacts relationships

A diagnosis of cancer has a 'ripple' effect across various aspects of a person's life. More than 45% of people affected by cancer say that the psychological effects are harder than the physical impacts, and 58% say that support for emotional needs is often lacking (Macmillan, 2009). As such, a more holistic view of cancer care is required.

Cancer does not happen in a vacuum. This means that ripple effects often extend outwards to the partners of people LWBC. As such, the shared relationship between couples is often impacted. It is for this reason, that cancer is often referred to as a 'we disease' (Dorvel et al., 2005; Berry et al., 2017). This is important as relationships are a significant source of support.

Key areas of a relationship which cancer often affects are daily/family life (Karracker and Latham 2015; Tranberg et al., 2019), communication (Badr and Krebs, 2013), intimacy (Berry et al., 2017; Li et al., 2020), social support (Ellis, 2012) and psychological challenges (Colbourne, 2005; Umezawa et al., 2015).

Taking this all into account, it's clear that cancer impacts individuals (and therefore couples) in a plethora of ways. The questions developed for our project were therefore based around these key topics which were explored during data collection and summarised on the following page.

Psychotherapeutic support and counselling

Cancer has an impact beyond the physical, so holistic care and support is an important consideration which are often overlooked.

Counselling is one method of psychotherapeutic support which can attend to this. Such interventions in the field of cancer tend to have a specific focus. Sometimes these are specifically for couples to focus on cancer related issues such as body image (Baucom et al., 2009), communication strategies (Notari et al., 2017), emotional expression (Baik and Adams, 2014) and developing a 'we' attitude in the relationship (Kayser, Watson and Andrade, 2007). This is the idea that couples develop a shared perspective whereby cancer affects both of their lives.

While issues such as these are extremely important for couples affected by cancer, we know that they do not often stand alone and tend to be interlinked. Yet, little research has explored how counselling can support couples in a holistic way with the wide-ranging and multifaceted issues which can affect relationships.



You've got 50 minutes every week for 16 weeks and when they're describing their treatment or their partner's treatment, you will say, "Oh, yes. So, it was four months of chemo and then actually he got sepsis and he was in hospital for a month." "Oh, that must have been awful?" "Oh, yes, it was awful." That's normally as far as that conversation goes with your friends and family. Obviously, as a counsellor, my role is to help them explore that and be like, "You don't have to just skip over that. You don't have to make that better for me. If you want to talk about it, let's talk about it. (Counsellor 1)



While there is an accepted need for more qualitative research in the field of cancer and relationships (Baik and Adams, 2014), we wanted to extend this further to find out if, and how, counselling has helped clients and their relationships.

Such research not only expands the field of knowledge, but is also argued to be potentially therapeutic and cathartic for participants to describe their experiences (Colbourne, 2005). With this in mind, collecting shared experiences of supportive interventions (such as WHY counselling) enables commonalities to be developed between experiences and shed additional light on holistic cancer care (Brandao, 2014).

The approach adopted for this study meant that 'critical moments' were gathered in terms of individual and partner experiences of cancer, but also, that of their counselling journey too (Soothill et al., 2001; Thomas et al., 2002). This not only responds to calls for research to be more focussed on couples (Dorvel et al., Keesing et al., 2016), but also extends the notion of critical moments beyond that of individuals, to the shared relationship too.

Methodology

Data collection



Phase One - online survey

A link to the open-ended survey was circulated to WHY members via email and posts shared on social media. Questions were based on findings from the literature review.

26

people LWBC

8

partners

41% response rate. Variation was achieved in terms of participant diversity; gender (f=28; m=5; undisclosed=1), age (51+yrs=25; 36-50yrs=3; 26-35yrs=3; undisclosed=3), and relationship status (married=23; together=5; separated=4; widowed=1; undisclosed=1).



Phase Two - interviews with counsellors

Interviews were conducted via Zoom with WHY counsellors. Interview questions were based on the key topics identified from the earlier conducted literature review.

5

counsellors

Interviews lasted on average 69 minutes. Variation in the sample was achieved in terms of; gender, time in counselling practice; time working for WHY; specialism (e.g. person centred, psychodynamic, creative, child, family, couples).

Phase Three - interviews with people LWBC and current/former partners

Interviews were conducted via telephone and Zoom. Questions were based on findings developed from phase one and two. Participants were recruited through the online survey and email to WHY members.

6

people LWBC

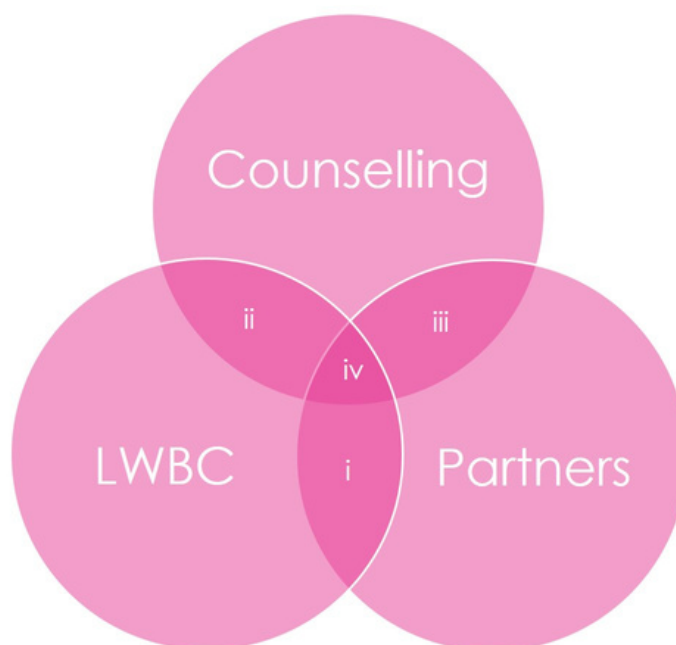
5

partners

Interviews lasted on average 65 minutes. Sample variation was achieved with gender (f=5, m=6); age (26-35yrs=1; 36-50yrs=2; 51+yrs=8) and marital status (married/ together=8; separated=2; widowed=1). All interviews were conducted individually, with the exception of one married couple who were interviewed together.

Data Analysis

Thematic analysis was carried out on all of the qualitative data generated from the project (Braun and Clarke, 2006; 2013). Data were coded and managed using the computer software Nvivo 12.



Findings were categorised into three (often overlapping) themes. Each of these three circles form a visual way to contextualise the findings for this report.

Unsurprisingly, cancer impacted people's lives in a plethora of ways. The intersection between the bottom circles (i) represents their shared relationship which cancer has affected. This is explored through pages 15-22 of this report.

We also found that counselling impacted clients individually (ii / iii), as well as in their shared relationship (iv). Also explored on pages 23 - 31 is the role of the counsellor, and more broadly, counselling as a psychotherapeutic intervention for people (and relationships) affected by cancer.

Finally, feedback specific to cancer counselling services is presented on page 32, with recommendations and future research directions on page 33.



Findings

Following analysis of the data, it became clear that cancer has a significant impact on adult relationships. A concept emerged whereby cancer acted like a magnifying glass on the relationship. It could highlight various factors within a relationship which fell anywhere on a 'positive - negative' continuum.

“ Now we are on two paths as separate entities. One being the cancer patient, and the other being the witness. (Survey #3) ”

“ I gave up my well paid (but crazily busy job) and he went part-time. We now have time for each other and are closer because of this. ”

At the positive end of the continuum, cancer was described to magnify the positive aspects of the relationship (e.g. bringing couples closer, enhanced communication, reassessing shared goals). This was likened to the relationship having 'strong foundations' which cancer (the magnifying glass) highlighted to clients.

In contrast, at the negative end of the continuum, cancer can magnify existing cracks in the relationship. For example, pre-existing communication challenges, change in the relationship dynamic (intimacy), and a couple's future/shared narrative.

The following sections of this report will unpack the findings underpinned by the concept of this continuum.

“ Where you have got faults in a relationship if you're under stress from the cancer, I would say I can see what people mean about it being magnified. But it's made me take responsibility for some of those faults. And I think if we hadn't had something like cancer come along, you wouldn't have challenged yourself [...] maybe something else might have challenged us, but cancer has been our thing.” (LWBC 3) ”



Findings - positive

While cancer clearly negatively impacted couple's lives in a variety of ways, many participants also explained some of the positives which had arisen, magnified as a result of cancer. As with the previous section, anonymous participant quotes have been included to contextualise each theme.

Enhancing

Frequently described was the perception of cancer enhancing, and bringing couples closer together.

"I think my partner having cancer really brought us closer together." (Survey 16)

This was often described through couples navigating a shared experience throughout the cancer journey.

"It's undeniable that the pair of us are changed through it, and our relationship, as weird as it sounds, probably in a positive way. You know, it will be something that we will always have shared together and navigated together. It is a bonding experience." (Partner 1)

There was a perception that this shared experience of cancer also provided increased opportunities to spend time with each other.

"In a way, my husband was one of the only people I could actually be myself with, and therefore, we were spending quality time together." (Survey 2)

This needed readjustment to the relationship through adapting activities and expectations.

"We addressed this by finding joy in the things we could do, and focusing on quality time together. We read extensively, often to each other. Whenever he was able, we would go outside for a walk, or for some short activities. But we adjusted to the requirements (I always had a backpack for the things he needed) and realigned our expectations for what we could do." (Survey 20)

Increased closeness within the relationship was also acknowledged in terms of intimacy between couples due to sharing vulnerabilities.

"There is a way in which some couples talk about greater intimacy because [of the sharing in] one person's acute vulnerability and need [for] dependency on the other." (Counsellor 5)

Reshaping life together

Focus was also directed towards how cancer could prompt couples to re-assess and reshape their future narrative and shared trajectory.

"I can no longer work so we are poorer, but have more time together."
(Survey 6)



"I gave up my well paid (but crazily busy job) and he went part-time. We now have time for each other and are closer because of this." (Survey 26)

This was also described in light of how cancer had imposed changes with roles in the family home. This subsequently had a positive impact on the relationship.

"[I have a] new role as housewife with a part-time job, and have had a few emotional wobbles as a result. However, I have adjusted and enjoy my new life; this makes me more relaxed and more patient in the relationship, which has made us closer." (Survey 19)

In some cases, this encouraged shared projects to develop and grow on the back of cancer. For one couple, this involved buying and converting a motorhome to offer increased opportunities for future special memories

"It was a great focus at a really key time. It was about a year after the first op, so it was January 2018 we got it [van]. We were planning it, we were visiting, it took quite a few months to organise and it was just a brilliant focus, wasn't it? Something new, something we both wanted to do together." (LWBC 6)

It was also perceived to be important to air pre-existing grievances or frustrations in the relationship. This allowed for stronger 'foundations' to be built for the future relationship.

"If they [LWBC] think they [partner] have not been listening to you, for goodness' sake, you have the chance to kind of start your life anew. You are building your new foundation." (Counsellor 2)

Communication

A common experience shared amongst participants was that cancer had a positive impact on communication within their relationship. For some, cancer prompted the ability to have genuine and authentic conversations with each other.

"We often spoke very candidly to each other about mortality and our own wishes." (Survey #20)

This reminded some participants of the strong foundations which had existed in the relationship before the cancer diagnosis. As such, reinforcing that the relationship was strong.

"His ability to do this also opened up the space for me to explore and try to explain what I was going through. So all the way through, we had moment of quite heart wrenching open conversations which really enabled us to navigate the huge mix of feelings, pressures and fears well together. It showed me that our relationship is strong as we are were able to deal effectively with a great deal of compassion and kindness with each other and the differing challenges we were facing" (Survey #30)

Knowing that the relationship had the capability to engage with open and honest communication, provided an additional sense of comfort and support for some participants.

"Well, just know that I can say anything to [LWBC] and he won't baulk. That kind of honesty means everything to me. And I completely trust that he loves me, and I know that I love him. Love is kind of like underneath everything and holding up everything." (Partner 5)



Also described was the importance of non-verbal communication, and how this changed within the relationship as a result of cancer.

"It also made me appreciate the importance of non-verbal communication in our relationship. The value of holding a hand, of simply being present." (Survey 12)

Protecting each other

Described by some participants was an underlying drive to protect and shield their partner from particularly challenging thoughts, feelings or emotions. While this was seen as a strength in the relationship, it was also described to be important that both parties have an independent means of venting and expressing some particularly sensitive concerns, beyond their partner.

"I can't talk about her death to her, for instance. I just wouldn't. We're trying to put those feelings to one side. I'm not suggesting for a minute that that's what I talk about all the time, but there are feelings that I have a handle around this, which I will feel comfortable sharing with her." (Partner 2)

For many participants, this required careful assessment of how they believed their partner was coping and feeling, before broaching some subjects. It was therefore important for couples adopt a high level of empathy and understanding of their partner's attitude and thinking at the time.

"I try to be mindful of how he's feeling and am careful when to broach a subject or talk about how I'm feeling." (Survey 12)

However, over-protecting and shielding their partner was also evident. It was therefore important to carefully balance this alongside also sharing some concerns. This suggests that while protecting their partner is important, also required is opening up and sharing of vulnerability.

"The problem I have sometimes with [husband] is that he's trying to be strong for me. So sometimes I don't see him being vulnerable and that's probably something that sometimes I do need to see. That's the only thing that maybe I worry about, because I worry about who he's talking to. I mean, he probably has got access to things if he looked, but I can't make him look he has to do that himself." (LWBC 3)



Findings - negative

Unsurprisingly, cancer impacted relationships in a myriad of negative ways. Some of the key themes are outlined on the following pages, illustrated by anonymised participant quotes to best exemplify findings.

Pre-existing cracks

Cancer undeniably has a major impact on relationships. For many participants, cancer magnified pre-existing cracks or flaws in their relationship. This was frequently described in terms of communication.

“ [Cancer] highlights and magnifies incompatibilities and communication issues in your relationship. (Survey #12) ”

For some participants, these challenges around communication within the relationship were always in place. However, the cancer diagnosis brought this to the forefront of the relationship.

"I communicate my feelings much more. Probably too much. I'm a bit unsparing really and I do find it easy to articulate my feelings and my husband finds it very hard to articulate how he feels. He's always had this problem anyway. Sometimes he finds it hard to know how he is feeling and he finds it hard to articulate." (Partner 5)

"When I try and broach things, he doesn't get upset, but it's never been our forte really to talk about emotional stuff. He'd say it is, if you talk to him [...] What he would say was a really good discussion, I think we were just 2% in. Just that different culture and different personalities. I don't think we've ever been particularly good about talking about emotions." (LWBC 1)

Extending this idea of communication further, cancer can also shine a spotlight on existing emotional issues within a relationship.

"It's highlighted emotional issues we've always had: my accusing him of having a 'narrow emotional repertoire' or being incredulous that he sees a 10-word answer adequate to something I would consider interesting, complex and worthy of a at least 2,000 words." (Survey #32)

Counselling, therefore, provided an opportunity to explore and understand where existing cracks may have existed in their relationship, prior to the cancer diagnosis.

"It [counselling] magnified to them [clients] that their relationship was strong already. I think it [cancer] also magnifies where the cracks are in a relationship. A bit like ice, and it opens up." (Counsellor 3)



Like ice in cracked brick foundations, cancer causes additional strain on existing weak points in the relationship.

"The impact of the cancer kind of just reverberates and people crack down their fault lines. So wherever there are existing vulnerabilities, then those can get expressed through issues relating to the cancer." (Counsellor 5)

Yet, for some couples, cancer allowed recognition of these existing cracks in the relationship. This provided an opportunity for reassessment, ultimately encouraging the relationship to grow and thrive.

"Where you have got faults in a relationship if you're under stress from the cancer, I would say I can see what people mean about it being magnified. But it's made me take responsibility for some of those faults. And I think if we hadn't had something like cancer come along, you wouldn't have challenged yourself [...] maybe something else might have challenged us, but cancer has been our thing." (LWBC 3)

"Something like a diagnosis of cancer shines a spotlight on, or can shine a spotlight on the very foundations of a relationship. Even the strongest of relationships. It brings a new challenge and I think that's something really important to acknowledge. It's existential." (Counsellor 4)

Shared narrative

A number of participants described how cancer impacted relationships in terms of future dreams and goals. For many, cancer brought these into question, or halted them completely.

"I feel like cancer takes away your future a bit. Although we are trying not to plan the future, you're part the reason he is doing what he is doing now, to make sure I can achieve what I want to achieve now, just in case [...] we're trying not to be negative about the future, but also trying to be realistic about what could happen."
(LWBC 3)

"A cancer diagnosis takes away your sense of future. Everything you thought you would do together as you age is thrown into question."
(Survey #8)

Some participants described how cancer forces couples into following separate pathways within the relationship.

"Now we are on two paths as separate entities. One being the cancer patient, and the other being the witness." (Survey #3)

"I think anything that challenges or throws into question that doubt or narrative. And in terms of relationships, I think its got massive repercussions. 'What do you mean this isn't going to be our life any longer?'" (Counsellor 4)

For some, changes in the relationship were most apparent in terms of hobbies and recreational time.

"It just seemed that we had moved very far apart. What I wanted weren't the things that he wanted anymore. It almost felt like he was reverting back to being a younger man." (Partner 5).

"Life became more unpredictable. Many holidays, events, social gatherings were cancelled at the last minute. We stopped arranging things into the future because her wellness or not was so unpredictable." (Survey 36)

Intimacy

Intimacy was discussed in a number of ways. Namely the importance of physical, social, intellectual and emotional intimacy. All of which were impacted by cancer.

"My diagnosis basically killed all intimacy and physical relationship with my partner overnight and this is still not back to normal, almost two years later. We cope with it, but it's an issue for both of us." (Survey #30)

"Physical intimacy is bit of an issue at the moment. I hugely lost confidence in my body. I don't know if other people have used this phrase, but I definitely felt 'betrayed' by my body." (LWBC 3)



Issues with intimacy within the relationship caused by cancer was similarly reinforced by partners.

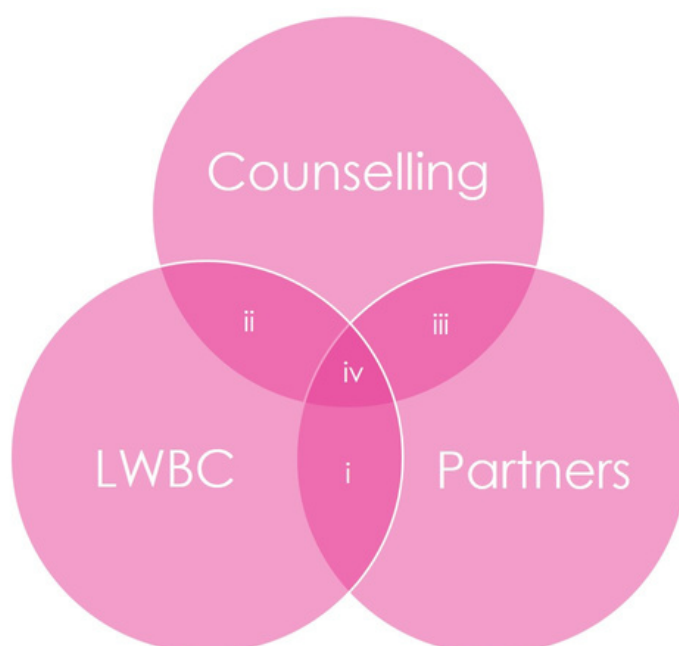
"Our physical relationship has gone. That has been a massive change and that's had a massive impact in lots of ways. It just changes your whole relationship. It's not just about the sex. It just changes the whole premise of your relationship really." (Partner 5)

Some participants who were not in a relationship described how intimacy was negatively impacted by cancer in forming future relationships.

"It's difficult to form relationships afterwards [...] I don't know why but I don't find it that easy to approach people." (LWBC 5)

"I'm grieving, not only for the loss of a woman that I was totally in love with, but also for the loss of the prospects of what she, or somebody else like her that I could meet [could provide], and the prospects of actually developing a relationship from scratch that held any prospect of being that enveloping." (LWBC 4)

Counselling



The final section of this report will focus on counselling in the field of cancer. This relates to the purpose and outcomes of counselling, specifically for individual LWBC (ii), partners (iii), but also, the purpose and impact of counselling on the shared relationship (iv). As with the previous findings sections, the following is based on data from all three phases of data collection and respective participant samples.



A unique conversation

Focusing firstly on the perspectives and data generated from the interviews with counsellors, the purpose of counselling is to provide clients with a unique type of conversation. Counsellors hope that clients are able to openly express thoughts, perceptions and feelings which were considered to be potentially harmful if discussed with their partner.

"I suppose the big part of the reason why counselling works and how it helps people is that it's a unique kind of conversation and relationship. [...] We're not here to talk about me [counsellor]. The idea is that we very rarely get that much time and space to actually just focus on how we're feeling without having to protect anyone else's feelings or preempt anyone else's reactions because the role of the counsellor is to be non-judgmental, and not bring use of preconceptions or prior assumptions about someone."
(Counsellor 1)

The purpose of counselling was perceived to provide an impartial space, solely focussed on a client's own experience of how cancer has impacted their life, and subsequently, their relationship.

"If somebody is interested in you and what you're bringing, and wanting to explore that with you, generally that leads people to feel 'okay, this is a space where I don't have to worry about this person'. Or you're picking up on you know you're picking up on those things. Like they might say, "Oh, how are you?" And you say "more importantly, how are you?" (Counsellor 5)

Furthermore, the knowledge that counselling is impartial provides an opportunity to express thoughts and feelings which are often withheld to protect loved ones.

"There's the therapeutic space, and actually that's been useful for the adults that I've worked with when they're trying to make sense of it for themselves. Having an impartial space, where they can step back and think about themselves, and 'other', you know that their partners, is a really, really helpful journey. It gives them a space where they can potentially say, or at least try saying, the unsayable, to begin with."
(Counsellor 4)



This was similarly reiterated by clients themselves. Counselling provided a seldom opportunity for clients to prioritise themselves and better understand how cancer impacted their lives.

"It sounds quite selfish, but that hour of counselling was about me, and the things that I needed, and that I needed to talk about. I actually found having that space, very important. It helped me get things straight in my mind about how I was feeling about stuff. And gave me that time that I needed to then be able to go home and continue to be supportive and caring." (Partner 1)

Importantly, clients benefited from not having to justify their experiences or feelings with their counsellor. Instead, clients had space to vent and explore with someone who was impartial.



"I think the most important thing for me is that allowed me to say things without having to tie it up in any sort of wording, or being concerned about how I delivered that information to someone else. There was complete objectivity and there was no emotional attachment [...] I could just say it. And the other really important thing was [that] it was someone who didn't know me." (LWBC 3)

Importantly, the specialist training of counsellors advocates a holistic approach to psychological wellbeing. This encouraged clients to explore how existing patterns of thinking would impact their reaction and experience of cancer.

"What happened in your youth and formative years actually forms the way you deal with stuff today. So you can't just start [reflecting/thinking] on the day the cancer was diagnosed because that's actually a relatively trivial part of the discussion [...] Counselling has helped me [...] become interested in myself [...] I've found out things that I didn't know." (Partner 2)



Past trauma

Discussed throughout the interviews with counsellors was the idea of previous traumas or historical experiences having an impact on a client's understanding or experience of cancer. Counselling therefore provides a way to explore these events which can (unknowingly) impact on a client's relationship.

"You can give the client a new experience of being able to talk about 'that' [past trauma] and to understand what's difficult about that for them, and [offer] a space for their feelings. Because usually, what you track it back to, is that they weren't allowed to express their feelings. Nobody really understood them back then, or their husband or their wife doesn't really understand them now." (Counsellor 5)

Exploring these past traumas during counselling allows for a new lens to view how their relationship has been affected by cancer.

"If we're talking about how cancer has affected their relationship. You've got time to ask about their previous relationships and how things happened then. They might be bringing feelings from that into this relationship. Or when they start talking about impact on their children or their parents." (Counsellor 2)

Crucially, counsellors found it necessary to revisit these previous traumas in order to adapt their understanding of how cancer has impacted their relationship.

"If they can resolve some of the stuff around that earlier trauma, it kind of opens up a window for managing this one [cancer ...] even if it can't be fully 'got over' in terms of they're going to live with cancer. They can live with it differently. So, as opposed to it being constant trauma. They can relate to that in a different way that gives them some power back. It's a bit of an empowerment thing [...] it goes back to their earlier experiences [of how] people relate to each other. How they've been depending, on how they had experienced." (Counsellor 3)

Such findings were reinforced by people LWBC and partners. Previous traumas in terms of past relationships were seen to be highly influential to how couples coped with cancer. Counselling offered a way to explore and better understand the impact on their current relationship.

"I was married previously, which I've kind of realised [...] through the counselling I received and was taking part in because of [husband's] cancer, it highlighted the problems that were going on in the first marriage. Abuse, which I haven't ever faced before. (Partner 5)

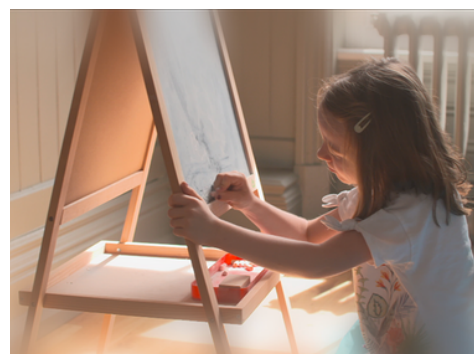
Similarly, talking therapies also enabled exploration and a light to be shone on previous relationship traumas, and how this impacts clients lives, now.

"All of the talk with the psychologist that I've seen on occasions at the hospital [...] has been about [how] I had a relationship that ended and I was grieving for that. I still am, to be honest. Three years now, but I'm still grieving for it." (LWBC 4)

Interestingly, while cancer was the main reason people initially sought counselling, much of what was discussed during sessions was often not explicitly cancer related, yet had a significant impact on clients. Counselling offers a valuable way to understand cancer through the lens of previous traumas. In many cases, this stems from childhood experiences.

"[Counselling] helped me to identify that I have a guilt connected to the fact that I was an adopted child." (Survey 9)

"That's where the counselling has really helped me. I've started to explore myself and you know some of the patterns of my behaviour, you think, well that was laid down in childhood. I've done that for 49 years. It's not going to change overnight." (LWBC 3)



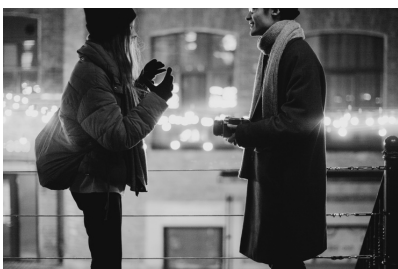
Understanding cancer

The purpose of counselling was also identified by counsellors to provide an opportunity to reflect and better understand their experience. The counsellors therefore highlighted the importance of sessions offering an opportunity for clients to outwardly discuss the intricacies and challenges associated with their cancer experience. Often this cannot be explored with friends/family, and so remains unprocessed.

"You've got 50 minutes every week for 16 weeks and when they're describing their treatment or their partner's treatment, you will say, "Oh, yes. So, it was four months of chemo and then actually he got sepsis and he was in hospital for a month." "Oh, that must have been awful?" "Oh, yes, it was awful." That's normally as far as that conversation goes with your friends and family. Obviously, as a counsellor, my role is to help them explore that and be like, "You don't have to just skip over that. You don't have to make that better for me. If you want to talk about it, let's talk about it." (Counsellor 1)

This was recognised to be extremely important as some counsellors acknowledged that not being able to fully process the experience may have a direct impact on relationships.

"Things like cancer, they're a harsh reality. A lot of people want to ostracize themselves from it. And that creates like a parting between them." (Counsellor 3)



Counselling therefore aims to provide clients an opportunity to express, process and understand their experience of cancer. In time, it is hoped this will lead to an element of acceptance in terms of challenging thoughts, emotions and feelings associated with cancer.

"The key challenge is to helping them to understand, or to own, that they can have nasty feelings. And it's okay for them to have those feelings and so the challenge is to help them to accept this and help them to express them." (Counsellor 2)

Perceptions of counselling offering a way to explore and better understand cancer were similarly reinforced by people LWBC and their partners. Counselling enabled clients to discuss particularly challenging aspects of their illness or treatment.

"I needed to be able to talk about my grief at my changing body, my feelings of being out of control during the investigations and treatment, (something that is a real issue for me) and my fear of death and the future, to someone who just listened, rather than tried to make things right." (Survey #19)

Similarly, the purpose of counselling for some participants was to process and reach a level of acceptance in terms of cancer, treatment and prognosis.

"I think one of the things we've talked about in my counselling sessions is this idea of a magic bullet. When you start out, you want the magic bullet. You want that cure, you want that thing. And if you look at cancer as a process and how the biology develops, there isn't going to be a magic bullet for cancer. There's not going to be a one drug fits all." (LWBC 3)

With this in mind, knowing that the counsellors were specialists in the field of cancer was a significant benefit. Counsellors were seen to have an in-depth understanding of how cancer impacts clients in various ways. Adopting this holistic attitude encouraged clients to feel like they were understood beyond the lens of cancer.

"The quality of the training and the consistency [...] there must be a lot of ongoing training and supervision and that kind of thing. I just think they are spot on. And of course, talking to people about cancer is their bread and butter, but they're not they're not confined to that." (LWBC 6)

"I would say there's an understanding about the whole thing about cancer, that there's a real feeling that you're being seen as a whole person and not just the cancer." (Partner 6)



Reassess, reframe and rebuild

The idea that counselling enabled clients to reflect and reassess their lives was described throughout all of the interviews with counsellors. In some instances, this was through the lens of cancer. Counselling offers clients a way to reframe how they can live alongside the diagnosis, without it becoming all consuming and defining of their character.

"It's about you giving them hope that life can be lived well, even in the midst of this awful thing. And whilst it takes up large parts of life, it doesn't have to subsume the whole of everything. And that can make people feel like they've got some life of their own. That's not just cancer." (Counsellor 3)

A fundamental aspect of counselling was therefore perceived to be supporting clients in rebuilding their life around cancer.

"So part of my job is to help them grow life around this because the reality is, it's going to be there, we cannot make it go away. We cannot give them assurance that is not going to happen again. But we can help them to, kind of, build life around it." (Counsellor 2)

Counselling was frequently described as a way to help people rebuild their life in the wake of cancer. People 'change' as a result of cancer. Counselling provides a way to reflect and incorporate these changes into the client's future. This was particularly apparent in terms of relationship dynamics changing as a result of cancer.

"What I always try to do is try to get out all this 'stuff' because if you think they have been rubbish. If they think they have not been listening to you, for goodness sake, you have the chance to kind of start your life in new. You are you are building your new foundation. Put all this information in, because otherwise you will be living this life with this sense of 'yes, but when this happened, you really didn't listen to me.' " (Counsellor 2)

This was apparent for participants who were LWBC and/or their partners. Counselling directly enabled some couples to take some time and reflect on how things had changed since the cancer diagnosis. This was perceived to allow reframing of experience.

"[Counselling] helped me to regain confidence and find a new part of myself that feels more able to face the future." (Survey 11)

Often this was described in terms of communication skills which had been nurtured during counselling.

"I think that's the counselling that's helped with that because they've encouraged us to be honest with them [children] all the way along and just say what's going on and when we can manage things and when we can't manage things, and when things are different. It's not been without its ups and downs." (LWBC 6)

Counselling was therefore described as having a significant (positive) impact on clients' relationships

"I felt listened to and understood. It felt like a safe place to unburden myself of all my pent up emotions which in turn helped me to reframe my approach to my partner and family." (Survey 12)

"I have been able to articulate some of what I was feeling with my husband, but this is only because counselling made me see it is OK to feel this/that." (Survey 19)



"Counselling was an important part of me being able to remain supportive of my partner whilst he was ill and build a strong relationship. It was my time to be sad and say how hard it was and that I was struggling, to give me the strength to go home and be everything that I needed to be." (Survey 20)

Counselling service feedback

Participants were overwhelmingly grateful for the cancer counselling service they received. Summarised positive feedback fell within the themes of:

Number of sessions

16 felt like therapy wasn't rushed compared to other interventions such as IAPT. This allowed for a sound relationship to develop between client and counsellor for more in-depth exploration of individual client case, traumas, and cancer experience.

Staff

The warmth, empathy and professional nature of both clinical and administrative staff was mentioned numerous times. Staff made clients feel completely understood and at ease right from the initial contact made with WHY.

Free of charge

This meant that clients did not have additional worry of finances to use the counselling services, especially when work/employment was often already negatively impacted by cancer.

Flexibility

In terms of different counselling services (group/one to one, outdoors), but also time and the location of sessions.

Continued support.

The ability to continue seeing counsellors within their private practice and utilise the professional relationship which had grown from the free sessions which had been provided.

"There's an understanding about the whole thing about cancer, that there's a real feeling that [with counselling] you're being seen as a whole person and not just the cancer." (Partner 4)

"[Re: counselling] I've got to say, it's almost as life saving as the surgery, to be honest." (LWBC 6)

Improvements

While the majority of feedback regarding counselling was positive, some areas of suggested improvements/critical feedback was also offered:

Standard treatment

Counselling to be seen by the NHS as an essential (and automatic) aspect of cancer care.

Additional services

For example, whole family approaches/days.

Offices and reach

A central building for counselling services to operate from. This would ensure better designed counselling rooms in terms of accessibility and atmosphere (e.g. rooms with windows).

Waiting time

This was the most frequently described point for future service improvements. Often feeling disheartened to find out that there was a long waiting list to start counselling after evolving to a frame of mind where clients felt ready to discuss their experience, then having to wait for availability. This tended to be framed by participants in a way that warranted more resources/funding to be made available in order to increase counselling availability.

Postponing or unable to finish programmes

Mainly due to Covid-19.

Ultimately, it's something that's very valuable. So it'd be good really if we got this [counselling] as part of the cancer diagnosis on the NHS." (Partner 2)

"I don't know if they do this, but they ought to be lobbying to have counselling as a standard form of conventional medicine treatment." (LWBC 3)

Lastly...

We would like to take this opportunity to extend our sincere thanks to all of the participants who took part in this project. Without their willingness to share their experiences, this project would not have been possible. Similarly, we are extremely grateful to the numerous people who formed the advisory panel and supported us throughout the duration of the project.

Finally, thank you for your interest in the project and taking the time to read this report. Please do not hesitate to contact us if you have any additional thoughts, comments or questions about the project:

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With best wishes,

Olly, Melissa, Charlotte and Felicity



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Who we support

- Carers
- Children
- Friends and loved ones
- Patients
- Relatives
- Young people
- Anyone bereaved by cancer or a life-threatening condition

Venues

- Bath
- Bradford-on-Avon
- Frome
- In various schools
- Midsomer Norton
- Online
- Street
- Trowbridge
- Warminster
- Yeovil

We Hear You receive no central government funding and rely entirely on client donations, local businesses, individuals, community groups and grant-making trusts.

If you would like to support our work, or find out more about the support we offer, please do get in touch.



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