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"I've got a very dichotomous difference in the way that I perceive myself": Positive and negative constructions of body image following cancer treatment

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RUNNING HEAD: BODY IMAGE FOLLOWING CANCER

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Abstract

This study investigated how women constructed body image following cancer. Four women, aged 32-67 years who had experienced breast or bowel cancer took part in a two-hour, in-depth focus group. Discourse analysis revealed that women orientated to positive aspects of the post-treatment body (silhouette, trust, acceptance) whilst acknowledging that their experiences were also traumatic (hair loss, scarring, sickness, swelling). Bodies and illness were concealed from public judgment, and women developed new trust in their bodies due to overcoming cancer; post-cancer bodies were accepted despite opportunities for normalisation. Implications for those wanting to support women during and after cancer are discussed.

Key words: breast cancer; bowel cancer; body image; discourse analysis; body acceptance; focus groups

"I've got a very dichotomous difference in the way that I perceive myself": Positive and negative body image experiences of cancer

Each year, around 173,000 women in the UK are diagnosed with cancer; breast cancer accounts for around 53,400 of those diagnoses, and around 18,400 women per year are diagnosed with bowel cancer (Cancer Research UK, 2017). Treatments such as surgery, chemotherapy, radiotherapy and hormone therapy can impact on how women's bodies look, resulting in potential body dissatisfaction and feelings of lack of sexual attractiveness (Baucom, Porter and Kirby, 2006; Brandberg et al., 2008, Burwell et al., 2006; Kissane et al, 2004; Williamson and Wallace, 2012). This study investigates how women who have had cancer and undergone treatment for breast and bowel cancers construct their body image.

There is relatively little existing research on impacts of cancer and associated treatments on women's body image, though women's bodies continue to be sexualised in popular western media (Bordo, 2003; Grogan, 2016; Jeffreys, 2014). Objectification Theory (Fredrickson and Roberts, 1997) focuses on the impact of existing in a culture that objectifies women's bodies, suggesting that women learn to objectify their own bodies, and would suggest that many women might find it difficult to come to terms with a body that differs from idealised sexualised media images. Women who have experienced cancer may have limited possibilities for controlling cultural discourses which position them as non-normative; it is therefore unsurprising that women who have experienced cancer often talk about the adverse impacts on their lives (Brunet, Sabiston and Burke, 2013; Parton, Ussher and Perz, 2016; Przezdziecki et al., 2013).

Many researchers have tended to assume that impacts of treatment will have a

completely negative impact on body image (e.g. Baucom, Porter and Kirby, 2006; Brandberg et al., 2008; Burwell et al., 2006). However, qualitative research using anonymous, open-ended questionnaires has suggested that responses to cancer and associated treatments may be complex, and not entirely negative (Altschuler, Nekhlyudov and Rolnick, 2008; Grogan and Mechan, 2016. Studies using one-to-one interviews have also shown that women may feel that breasts are functional but also dispensable (Holland, Archer and Montague, 2016); scars may be perceived as reflecting a successful journey to recovery (Wallace et al., 2007), and hair loss resulting from chemotherapy may be seen as a sign of bravery (Boehmke and Dickerson, 2005), and an outward signifier of illness and reduced abilities that may be socially useful under some circumstances (Harcourt and Frith, 2008).

Previous qualitative work in this area has tended to use one-to-one interviews (e.g. Harcourt and Frith, 2008; Holland , Archer, and Montague, 2016;.Wallace et al., 2007), or open-ended questionnaires (e.g. Altschuler, Nekhlyudov and Rolnick, 2008; Grogan and Mechan, 2016). Wilkinson (2000; 2015; 2016) has shown how focus groups, where women are given the opportunity to share experiences of cancer and cancer treatment with other women in a similar position, can be effective ways to understand women's constructions of breast cancer. In her focus groups with women with cancer, she found that the supportive environment facilitated openness and disclosure, and that focus groups, where women co-construct meaning and share experiences of a similar life event, can be useful in understanding some of the complexities inherent in women's experiences of breast cancer. Showing how women support each other in this kind of group, she points out that participants' interactions with each other enable the researcher

to gain a fuller and richer understanding of how cancer is constructed; this goes beyond what is possible in a one-to-one interview with a researcher, however skilled the researcher. Focus groups also enable women to follow their own agendas and use their own language and concepts. Her work suggests that focus groups may be effective means to enable free, relatively naturalistic, and positive discussions amongst women who have shared challenging experiences.

The Current Study

This study set out to examine both positive and negative constructions of body image after cancer and associated treatments, using women's own accounts to ground the analysis, as suggested by Holland and colleagues (2014). Using focus group methodology enabled us to capitalise on the strengths noted above, such as support, co-construction of meaning, and increased disclosure (Wilkinson, 2000; 2015; 2016), and giving women some control over the focus group agenda left space for unexpected findings, and positive as well as negative constructions of the body. Our analyses aimed to highlight cultural meanings as these women who had undergone breast or bowel cancer treatment reflected on their everyday experiences. In particular, we were interested in how these women's talk resisted social norms around women's bodies and cancer.

Research Question: How do women construct body image following cancer treatment?

Method

Design

A qualitative approach was adopted, focusing on the personal experiences of women following cancer. Women took part in one focus group, facilitated by the second and

third authors, and supported by the fourth author. As mentioned above, focus groups are particularly useful for enabling people who have experienced similar events to speak freely about their experiences, and have been used effectively by others who have focused on women's experiences of cancer (e.g. Wilkinson, 2000, 2001; 2015; 2016). Women were encouraged to talk freely about their experiences and discuss with one another, and the session was broadly structured around some key questions which appear below.

Recruitment

Women were invited through an advertisement placed on a UK cancer charity website, and were asked to take part in a study to investigate stories and personal experiences of cancer diagnosis and treatment, as part of a larger study on "creating unique garments inspired by research images, techniques and stories for display at the European City of Science Festival 2016". To be included in the study, women had to have had a personal diagnosis of some form of cancer and be comfortable talking about body image. Women were told that they would be supported by the Research Engagement Manager for the cancer charity (fourth author) when they attended the workshops, and that they should set aside up to four hours, and that their travel costs would be paid.

Participants

Four, English-speaking women were recruited. Pseudonyms are used below to protect the identities of the women involved in the study.

"Annie" is a woman aged 42 with a diagnosis of a rare bowel cancer. The disease and her treatment pathway have resulted in significant weight loss and have included radiotherapy and surgeries to remove a tumour obstructing her bowel (4 years ago), with

permanent scarring on her abdomen and ongoing screening.

"Delphi" is a woman aged 32 years with a history of more than one cancer: her first at the age of 12, and most recently a diagnosis of breast cancer. She has had a double mastectomy and reconstruction which has resulted in scarring. She has also had chemotherapy and hormone therapy with side effects including weight gain and hair loss.

"Ebony" is a woman aged 67 with a diagnosis of breast cancer. She has had breast conserving surgeries and radiotherapy which has resulted in breast indentation and scarring.

"Noor" is a woman aged 50 with two diagnoses of primary breast cancer; fifteen and ten years before the focus group session. Her treatment pathway has included surgery (single mastectomy 15 years ago), and radiotherapy and chemotherapy (15 and 10 years ago), which have resulted in some scarring, weight gain and lymphedema.

Materials

A semi-structured schedule was constructed using previous literature including Grogan and Mechan (2016) as guides. Women were asked questions about their bodies first such as: "First of all, we asked you to have a think about your body and changes since your diagnosis, does anyone want to share any thoughts on this? Who would like to start on this? [as each person shared their piece of text/thoughts] Thank you for sharing that. Does anyone else have any comments to make on hearing that story? [probe: anyone else?][Continue until everyone who is comfortable to do so has shared stories] Thank you all for sharing your stories. Can you tell us a bit more about your body prior to your cancer diagnosis? [probe: can you tell me any more about that]. Can you tell us a bit more about how you feel about your body currently? [probe: Can you tell us a bit more about

that?] Has having cancer changed how you feel about your body in any way? Are there any occasions where you have felt particularly good about your body? [probe: Tell me a bit more about how you felt] What are the key challenges at the moment in relation to your body image [probe: Can you tell me more about that?] Are there any strategies that you use to feel positive about your body that we could pass on to other women? [probe: Can you tell me a bit more about that?]. Finally…is there anything else that you would like to add?

The Research Team

Focus groups were facilitated by the second, third and fourth authors. The second author is a woman in her 40s who is a lecturer in Apparel. The third author is a woman in her 20s, who is a PhD student researching behaviour change and body image. The fourth author is a woman in her 20s who works for a UK cancer charity. The first author is a woman in her 50s and has a research interest in women's body image, including in women who have experienced cancer. The fifth author is a male social psychologist in his 40s with expertise in body image and discourse analysis and was only involved in the data analysis and write up. All authors agreed the final analysis.

Procedure

Ethical approval was first gained through [blinded for review] University ethics committee. Women were asked to think about their bodies prior to attending the session and were encouraged to write down some of their feelings and experiences ahead of coming to the group. After arrival, the second author then presented an introduction where she explained the aims of the study, anonymity and right to withdraw. Consent forms were then distributed and an ice-breaking activity was conducted where women

were asked to create a name for themselves to be used for the study and in reports. All areas were then covered as in the Materials section above, ensuring that all women in the group had an opportunity to respond in full to each question/topic, and that any areas considered important by the women themselves were followed up so as not to restrict what they said. At the end of the session, women were given a full debrief, and given details of the team and support services in case they wanted to follow these up.

Once the analysis was complete, the four women who took part in the interviews were sent a draft of this paper for comment, and were asked to add anything at all to the descriptions of themselves and to the paper as a whole; all responded with some minor additions/changes, and all approved the paper as a fair summary of the focus group and their accounts. After further revisions, we emailed them to give them another opportunity to comment/make changes to the final version of the paper. Only Ebony responded to our e-mail request saying "I have read through the paper again, and it all seems perfect".

Analysis

We undertook a discourse analysis (Potter, 1996), informed by features of discursive psychology (Edwards and Potter, 1992) and conversation analysis (Sacks, 1992). In discourse analysis, talk is understood as a form of action designed by speakers for a specific context, and thus it does something relevant to, and is occasioned by, that context (Potter, 1996). Talk about people's experiences of having cancer can therefore be analysed as "a performative domain of social action where identity construction is part of the practical activity of defining an illness and explaining its causes", outcomes and impacts on the self (Horton-Salway, 2001, p.248). Our analysis of the participants' conversation followed three steps (Edwards and Potter, 1992): locating the central

themes that are named and/or implied in the talk; focusing on the discursive activities within each section; and examining how respondents (co-)constructed accounts (see Baker, 1997 for more on the co-construction of accounts in talk). During the analytic process the authors worked together to evaluate the results and successively plan further development of the analysis. The extracts are presented as transcribed, and in sequential order, although some have necessarily been truncated due to journal word limitations.

Results and Discussion

Although our focus group participants talked about some of the unfavourable experiences during and post-cancer treatment, they also talked positively about their experiences. We argue that this can be viewed as managing and resisting societal notions about their bodies (also see Little and Sayers' (2004) extended interview research on hope, and Kaiser's (2008) interview research on survivor identity); for example, identifying the body as "dichotomous" with both positive and negative impacts, concealing the body and illness from public interest and judgment, increased trust in the body from its ability to overcome cancer, and acceptance of their bodies though rejecting opportunities for modifications such as breast reconstruction. We begin our analysis with participants Delphi and Annie responding to the moderator's invitation to discuss their experiences of cancer and treatment in relation to their bodies:

The dichotomous body

MODERATOR: Thank you. OK, so this first part of the session we're gonna just talk about um the body really... um and your um your experiences with the body .. So um we asked you to have a think about your body, yourselves um does anybody have anything to share you've thought of before you got here; it can be anything at all… in terms of your experience.
DELPHI: I think for me personally I've got a very dichotomous difference in the way that I perceive myself now to prior to having had breast cancer...um...so actually my physical shape and outline is better than it was previously because my surgeon is a genius.

Um...but…there are an awful lot of aspects that have through chemotherapy um and various other things um become really upsetting um I would say being the closest word to it...So thinning hair, lack of eyebrows... generally my skin and complexion is completely different um...I'm allergic to everything (laughter) um…and I find that's so..,so that's, it's sort of strange the sort of differences between the two um...And also my unclothed form with all the scars and all the things so whilst my silhouette is um I find much nicer um.. mmm…my...body I wouldn't want to expose all of the scars um and things so that's that's quite an issue.

Delphi's response recognises her experience as likely to be unique "for me personally" and positive "my physical shape and outline is better than it was previously"; a non-typical reported experience (Brunet, Sabiston and Burke, 2013; Parton, Ussher and Perz, 2016; Przezdziecki et al., 2013). But, Delphi's positive response also sets the tone and context for the subsequent conversation (Sacks, 1992). In other words, exchanges tend to occur in pairs, so that if someone begins with positive and/or a negative experience successive speakers may also be compelled to do so. Delphi provides an account of her chemotherapy treatment "through chemotherapy…things um become really upsetting" (see Edwards and Potter, 1992 for more on how participants manage their stake in interaction). Delphi bolsters this latter experience with a list of chemotherapy impacts on the body "So thinning hair, lack of eyebrows... generally my skin and complexion". Jefferson's (1991, p.68) work on listing suggests that speakers and hearers use lists as an 'orientated-to-procedure', providing the speaker and hearer with a means to discursively position themselves in relation to the items on the list as well as providing other participants with a means to accord and monitor group status (Widdicombe and Wooffitt, 1990); that is, whether the person's experience is legitimate to be considered as a member of the identity category 'people who have experienced cancer'.

Several other things are noticeable from this extract. Firstly, the way in which Delphi constructs her account suggests talk about the experience of cancer is 'delicate'

(Silverman and Peräkylä, 2008). Parton, Ussher and Perz's (2016: p.490) thematic analysis of in-depth semi-structured interviews with women who had experienced cancer identified 'the abject body' discourse, which constructs women's bodies 'outside idealised discourses of embodied femininity'; women must manage their post-cancer treatment body in relation to this social discourse. However, women can also resist such discourses, and we get a sense that Delphi does this when she suggests her "physical shape and outline is better than it was previously".

In the following extract, Annie talks about her positive and negative experiences emphasising that her naked body was the main issue post-treatment:

> ANNIE: Yeah I was making some notes on the way here on the train um, so I I didn't have breast cancer... um... as you know... I had um cancer in my bowels and a complete bowel obstruction where it was an absolute and complete... So I couldn't eat and then after my surgery um I lost a lot of weight, so I lost about 2 and a half stone so I was literally skin, skin and bones um and I lost most of my sort of breast tissue so um I've a much smaller bust um and a very scarred abdomen because although they did keyhole surgery which was supposed to involve less scarring it actually involved um quite a large - because they had to take the tumour out in one piece - quite a large scar still and then three other scars so the stomach was quite patchwork and then I had a wound infection so um... it's also quite misshapen as well so.... a bit like you (*to Delphi*) um I don't um mind my silhouette too much um but I have more issues, much more issues with my sort of naked self um because I don't look like myself um and I didn't feel like myself for a long time afterwards.

Annie's personal experiences centre on her having had bowel cancer rather than breast cancer as experienced by the other focus group members. She lists her experiences as a significant loss of weight "I couldn't eat…I lost a lot of weight…I lost about two and a half stone…I was literally skin, skin and bones", and some post-surgery scarring (Jefferson, 1991). These are adverse health, body and image-related impacts, but given that Delphi had set the tone and context of the discussion to include positive experiences, and given also that group identity is based on shared experiences, Annie's response

orients to the preference for agreement (Pomerantz and Heritage, 2012). Annie does this by orientating toward Delphi's account of her body in clothing "a bit like you…I don't um mind my silhouette too much" (Sacks, 1992; Widdicombe and Wooffitt, 1990).

The concealed body

In Annie's account above, her main concern is with her naked body "I have more issues, much more issues with my sort of naked self". This suggests a dissonance between the public presentation of the body and her self-perception. Goffman's (1959) dramaturgical 'front and back stage', would suggest that these women aim to present their post-cancer bodies as positive/normative (front stage) whilst not necessarily feeling comfortable with their naked body (back stage). The positive/normative presentation of the public body indicates a level of resistance to negative social discourses in which the post-cancer 'survivor' feminine body is constructed as incomplete and less feminine (Brunet, Sabiston and Burke, 2013; Kaiser, 2008; Parton, Ussher and Perz, 2016; Przezdziecki et al., 2013). This type of resistance was common, and focus group participants spoke about the use of cosmetics, wigs, prosthetic devices and types of clothing to hide any perceived body imperfections. For instance, Delphi says "I had a whole selection of great wigs because I thought at least I'm gonna enjoy it! ". Women also spoke about avoidance of public spaces, and the management of their naked bodies by "hiding" them in those spaces such as public changing rooms. For instance, Noor says "I would go to the gym and strip off and go into the shower... and... you know... But now I don't do that... now I hide myself in a little corner".

In the following extract, we show how participants resisted public interest and judgment by concealing their illness:

> NOOR: You know I'm thinking "oh my God" I didn't tell a lot of people apart from immediate family, and my immediate family is very big you know and second time I did lose my hair so...wearing a scarf was...okay being Muslim and everybody would associate "oh she's just started wearing the scarf"
> DELPHI: And also, I guess the way that you project yourself, that you're not doing it because you decided that's what you're going to do now...and, you, I...there's sort of...I...it's like not really definable essence of...of...you kind of...if you're uncomfortable about it, or if you're, if it's something different that wasn't something that you chose to do...you kind of project...that something.

Noor "didn't tell a lot of people apart from immediate family", and the clause "and my immediate family is very big" suggests that there might be limitations on the number of people from whom one can conceal one's illness. Noor's links her form of concealment "wearing a scarf" to other people's expectations based on her "being Muslim". Delphi re-orientates the conversation to a less culture-specific experience of body concealment that is likely to be shared by all group members "the way that you project yourself". That is, one should project oneself as if one did not have breast cancer (see Shelley, Rosemary, Joanne and Wood, 1985). These extracts show how women concealed their bodies from others, managing other people's awareness of their illness.

The trusted body

Despite issues with the management of the public body some participants talked openly about how they had developed renewed trust and respect for their bodies as a result of cancer treatment and survival. For instance Delphi talks about having "a really huge respect" for her body:

> DELPHI: I know that I can, you know I've found a good doctor who I just ring him up and he's like go for blood... You go have that test, you told me what you want... and so I now have that, I'm, I'm particularly blasé about everything because I just get better, that's just... it's done it before it can do it again so I do have like a really huge respect for the capabilities of my body

In this extract, Delphi focuses on her body's ability to survive cancer "it's done it before it can do it again", emphasising resilience and ability to survive. In the following extract, Annie also discusses how she has developed "trust" and "new found respect" for her body.

> ANNIE: So...yes and so now I can as I say look at myself in the mirror now and accept it as it is um, there's elements as well of um...sort of...having like a new-found respect for your body, that you can have this major thing wrong with you, and have this major surgery and come out the other side...um…that so...I suppose there's like a feeling of sort of...strength and sort of like trust sort of in my body that I maybe didn't have before, you know maybe that it's...that it's gone through that and got to the other side…and that and as you say, that you are still here...um..

In this extract, Annie works up an account of her body's resilience "you can have this major thing wrong with you, and have this major surgery and come out the other side", "having like a new-found respect for your body", whilst also acknowledging she still has issues "there's elements as well of um...". Quotes from Delphi and Annie suggest resistance to social discourses that position those who have experienced cancer as only having adverse body experiences (Brunet, Sabiston and Burke, 2013; Przezdziecki et al., 2013; Shildrick, 1997).

The accepted body

All participants indicated they accepted their post-cancer bodies. For instance, Annie "I sort of, I have accepted sort of who I am ". Acceptance can be a form of resistance to social discourses which position a woman's post-cancer body as incomplete and less feminine (Brunet, Sabiston and Burke, 2013; Kaiser, 2008; Parton, Ussher and Perz, 2016; Przezdziecki et al., 2013). In the following sequence, we show an additional dimension of acceptance and resistance; the rejection of breast augmentation. We join the conversation after Annie has been discussing how different people respond to breast

cancer. She talked about one woman's experience "she'd had sort of breast augmentation because she was being unhappy that she had sort of one breast that was much larger":

> NOOR: Yeah. I still...you can sort of, cos there's no time limit on it, you can go anytime to have your surgery...you know...It's whenever you're ready, if it's ten years after fifteen twenty, it can be...But it's how you feel, and sometimes I think..."should I" you know but then it's...I can't go through that six months…sort of post-op...you know recovering and even then it's not fully and I just...I can't...and sometimes I think like you say...it's a blessing that the cancer came in my breast so it can be removed rather than anywhere else, if it wasn't seen.
> EBONY: Well you see I, I know what you mean there because I know...how massively lucky I was but my worry about that if I have any reconstruction because it's very weird is...don't push your luck, they got it out...everything's fine...why would I bother interfering with it...It might just start something off...So that's why I haven't, although I don't like the look of it and it's horrible, um...I just think (--) it's out, it's as far as I know, hopefully it's over...Move on...Be thankful...so that's why I haven't.

Noor agrees with Annie "Yeah" before pointing out that she "I still" and the group members "you can" have breast augmentation surgery at any time "you can go anytime" "It's whenever you're ready". What is interesting about these non-time markers "you can go anytime", "if it's ten years after fifteen twenty" is that they summon discourses of choice, individual agency, individuality, and self-respect because they position the individual as in control of her body. However, conversely, what is achievable is constrained by self-policing "I can't go through that six months…sort of post-op", "everything's fine...why would I bother interfering with it...It might just start something off". Thus, what we see in this short sequence is a co-constructed account of accepting the post-treatment body, and the rejection of breast augmentation framed as a cancer returning risk.

Implications

Our analysis has shown that post-cancer treatment identities were co-constructed during the focus group interaction on a moment-to-moment basis (Antaki and Widdicombe,

1998). During the conversation, interactants could be seen to orientate to positive aspects of the post-treatment body (silhouette, trust, acceptance) whilst acknowledging that their experience was also traumatic (hair loss, scarring, sickness, swelling etc.). There was also a sense that discussing experiences of cancer with others who had not had cancer was a 'delicate' topic (Silverman and Peräkylä, 2008) in order to avoid others viewing them through the lens of sick or incomplete body discourses. Participants provided accounts of how they managed their 'stake' (Edwards and Potter, 1992) by identifying the experience of cancer as having both positive and adverse impacts. Resistance to social discourses suggested these women had started to develop new body identities, accepted their bodies, and trusted and respected their bodies now that they had shown that they could withstand serious illness. Results support Zebrack (2000), who has argued that people may be inspired to create new body identities as a result of cancer, and also other work with women who have had mastectomies (Grogan and Mechan, 2016).

Clearly women's experiences of cancer are complex. They may be under pressure from others to 'get back to normal'; to be survivors (Wilkinson, 2000). Having survived a serious illness, it may be difficult to admit to feelings of body dissatisfaction and unease without risking being labelled ungrateful and vain, and it is important to acknowledge that feelings of concern about appearance are a valid part of their experience. Annie and Delphi were particularly concerned not to appear vain, and Ebony repeated how lucky she felt to have survived cancer, saying "I do know how massively lucky I was". The focus group context gave women space to talk about body-related challenges with other women who had also experienced cancer without fearing being judged negatively. This enabled women to co-construct both positive and negative meanings associated with

body image, embodiment, and cancer treatment, and highlighting some of the complexities inherent in women's body related concerns following cancer.

Strengths and Limitations

Participants were detailed in their responses and shared a lot of personal information, which was a key strength. Asking women to think about their bodies and changes since their diagnosis before coming along to the focus group enabled them to think about what aspects of their stories to share, and we would use this method again if we re-ran the study. This study also broadened the participant pool beyond focusing on breast cancer. There were also limitations inherent in our work. We recognise that some of the research team were involved in co-constructing the data as participants in the focus group, and that this may have impacted on the data. The accounts also come from a limited number of women who were all based in the UK, so we do not know how far their responses would generalise to other women who have experienced primary cancer. Further research could examine this through selection of a wider group of women from varied geographical areas, with secondary as well as primary cancers and a wider age range, to enable greater understanding of possible diversity in views in women with various types of cancer and different treatment pathways.

Reflexive Summary

As researchers, we have tried to present women's accounts fairly and disinterestedly. The research team includes women of a range of ages and experiences, with academic expertise in health psychology and apparel, as well as professional experience of working with women with cancer, and personal experience of cancer treatment. Our analysis has been ratified, and developed, by the women who took part in our focus group. The

analysis benefits from including different perspectives on cancer and body image, and results shed additional light on women's constructions of their bodies following cancer.

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