Patterns and predictors of disclosure of a diagnosis of cancer

Heather Munro 1*, Suzanne E. Scott², Alex King³ and Elizabeth A. Grunfeld⁴

¹Central and North West London NHS Foundation Trust, London, UK

*Correspondence to: Central and North West London NHS Foundation Trust, Palliative Care and Oncology Service, The Furze, The Hillingdon Hospital, Pield Heath Road, Hillingdon, UB8 3NN, UK. E-mail: heathermunro@nhs.net

Abstract

Background: The value of talking (i.e. disclosing ones innermost thoughts and feelings) has been recognised as playing an important role in helping people work through their difficulties. Although disclosing a diagnosis of cancer has been identified to be one of the hardest aspects of having the disease, relatively little is known about the extent to which people talk about their diagnosis of cancer. This study aimed to identify disclosure patterns among patients with cancer and to determine the factors associated with disclosure.

Methods: Patients (n = 120) who had received a diagnosis of either lung, colorectal or skin cancer completed a questionnaire assessing potential psychosocial predictors of disclosure.

Results: Results indicated that the majority of patients (95%) found it helpful to disclose information and did so to a variety of social targets, with the highest levels of disclosure being reported to medical personnel (38%) talked 'very much'), followed by family members (24%) and then friends (12%). There were no differences in disclosure across cancer types, with the exception of patients with colorectal cancer who disclosed information more to nurses and other cancer patients. Men disclosed information more than women to some social targets. Dispositional openness (B=.233, p<0.05) and treatment type (B=-.240, p<0.01) were found to predict 13% of the variance in degree of disclosure.

Conclusions: The results suggest that individual differences and social and clinical factors impact on disclosure and that medical professionals play an important role in the disclosure process. Copyright © 2014 John Wiley & Sons, Ltd.

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Introduction

Disclosing a diagnosis of cancer to loved ones is reported to be one of the most emotionally difficult aspects of having cancer [1]. Disclosure has been defined as being the extent to which patients openly discuss with others their diagnosis and thoughts and feelings about their disease to a range of social targets [2–4]. Disclosure is considered an ongoing process with many complexities including who is told (e.g. friends, family, healthcare professionals and colleagues), what and how much is said, whether it is planned or unplanned, or deliberate versus brought about. Disclosure involves a dyadic interaction where there may be responses, questions and concerns on both sides [5].

In qualitative studies of disclosure, patients have reported feelings of sorrow when witnessing the pain of loved ones, guilt for causing this upset [1], and worry that disclosure may result in emotional anguish for family members [1,6]. Despite this, the literature on patients with breast cancer has found that the majority of patients do disclose and that total concealment is rare. For example, less than 8% of patients with breast cancer report little or no disclosure beyond their spouse or doctor [3,7].

The wider literature suggests that sharing information about oneself is beneficial [8] with links to better physical health outcomes [9]; it facilitates in-depth conversations and formation of meaningful relationships [10]. In contrast, non-disclosure (differentially referred to as concealment, repression, inhibition, secrecy and topic avoidance) is largely considered detrimental, leading to awkward, superficial, stilted and dissatisfying interactions and relationships [11,12]; greater anxiety and lower emotional well-being [13–15].

Among patients with cancer, disclosure allows the individual to process cancer-related concerns, provides opportunities for validation and helps find meaning in the experience, all of which facilitate adjustment [16,17]. Disclosure has been linked to better psychological well-being and quality of life [18], greater levels of personal growth [19], and better marital relationships [20].

Despite the apparent benefits of disclosure, self-concealment is sometimes used by staff and patients as a form of coping in oncology settings [21]. Patients, and their spouses, can engage in 'protective buffering' [18], whereby they avoid discussing their fears or concerns in order to protect the other person [22]. However, concealment can lead to increased isolation from usual support networks [23], lower relationship satisfaction, poorer mental health [24], lower levels of social support and higher levels of unsupportive social interactions [2].

²Unit of Social and Behavioural Sciences, Dental Institute, Kings College London, London, UK

³Imperial College Healthcare NHS Trust, London, UK

⁴Applied Research Centre for Health and Lifestyle Interventions, Faculty of Health & Life Sciences, Coventry University, Coventry, UK

Although there is general consensus that disclosure is beneficial, negative consequences of disclosure have also been reported by patients with cancer, including changes in the way that they are perceived by others [7], a loss of control and autonomy, and strained relationships. Furthermore, rather than mobilising support, those who receive disclosures to can become distant [6].

The types of reactions people receive in response to their illness may impact on future disclosures, particularly if those responses are found to be unhelpful [2]. Stigma has been highlighted as a factor that is relevant to disclosure across a variety of health conditions [25,26]. Patients with cancer have reported stigma associated with the disease [27] and have reported avoiding disclosure because of concerns about being stigmatised [28].

Research into this subject would allow insight into what drives or hinders disclosure. This, in turn, could be used to assist and support helpful disclosure, thus improving adjustment to the experience of being diagnosed with cancer. The only known multivariate study that has considered the determinants of disclosure found that, in patients with breast cancer, age, disease severity, optimism, stressrelated growth, and disclosure attitudes predicted 26% of the variance in disclosure [3]. The present study expands on this by measuring disclosure in a sample with a range of cancer types, including men and women, and by considering a range of other factors that may conceivably impact on disclosure (e.g. social support, stigma and psychological distress). The study aimed to: (a) quantify the degree of disclosure across social targets, (b) determine the factors associated with disclosure, and (c) explore whether patients perceive disclosure to be helpful.

Method

Procedure

Participants were identified and recruited by cancer nurse specialists at a large London teaching hospital. Inclusion criteria were as follows: (a) aged over 18 years, (b) a recent (between 8 weeks and 2 years) first time diagnosis of either skin, colorectal or lung cancer, and (c) sufficient English language proficiency to complete the questionnaire. The lower boundary of at least 8 weeks was chosen to ensure that enough time had passed since diagnosis to allow for the opportunity to disclose information. The upper limit of approximately 2 years was used to optimally enhance the self-report data because recall of information about the diagnosis and disclosure period may erode with increasing time spans since the event of disclosure. The three cancer types were selected as they are common cancers for both men and women. Patients with secondary or metastatic cancer were excluded so that it would be clear which diagnosis and disclosure-related period the person had to remember. Those receiving palliative treatment

were also excluded to prevent overburden. Potential participants were either given a recruitment pack in the clinic (skin cancer) or sent the pack in the post (colorectal and lung cancer) that contained a cover letter, an information sheet, the questionnaire booklet and a Freepost envelope. It was possible to opt out of the study by returning a reply slip. Where no response had been received after 3 weeks, a follow-up reminder letter was sent to those in the colorectal or lung cancer groups. The study protocol was approved by the South East London Regional Ethics Committee (reference 11/LO/0341).

Primary outcome measures

Degree of disclosure: A single item ('How much have you talked to the following people about your cancer?'), modelled on that used by Henderson et al. [3], measured the extent of disease disclosure across a range of social targets. In line with Henderson et al., the range of social targets were similarly categorised into three main groups: family members (spouse, siblings, children and parents), friends (friends/neighbours, co-workers, and other patients with cancer), and *medical personnel* (doctors and nurses). Other social targets were 'professional therapist/counsellor' or 'minister, rabbi, and pastoral counsellor'. The categories were 'did not have the opportunity to talk (0)', 'purposefully chose not to talk (1)', talked a little (2)', 'talked somewhat (3)', and 'talked very much (4)', with higher ratings indicating greater levels of disclosure. The current measure expanded the scale previously used by Henderson et al., by delineating between 'purposefully choosing not to talk' and 'did not have the opportunity to talk'. It also separated the 'parents' category into two items, one for 'mother' and one for 'father'.

Mean level of disclosure was used to represent the degree of disclosure. This was calculated for the family members category, the friends category and the medical personnel category as well as an overall mean across all social targets. The internal consistency of the scale used in this study was found to be 0.77.

Helpfulness of disclosure was measured in two ways: (a) a single item, a global index of helpfulness by asking patients to rate how helpful/unhelpful it had been to talk about their cancer (0 = 'very unhelpful' to 5 = 'very helpful') [4]. (b) Two open-ended, qualitative items developed for this study asked patients to specify the ways in which disclosure had been either helpful or unhelpful (wording of questions: 'Please specify in what ways it was helpful to talk to others'/'Please specify in what ways it was unhelpful to talk to others'). The written responses generated by these items were analysed using thematic analysis [29]. Themes were identified both at an explicit level, where they were directly manifested in the written descriptions (e.g. use of the word 'stigma'), as well as at a more latent or interpretative level (e.g. a sentence that alludes to the

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sense of stigma without directly stating the term). The initial themes were then re-examined to ensure that they accommodated all of the data, and a clear definition for each theme was generated. Responses to the open questions were then rated for the presence or absence of each theme by two separate raters (HM and SS) to determine the proportion of patients who expressed each view.

Psychosocial measures

Perceived social support was measured using the Enhancing Recovery in Coronary Heart Disease Patients Social Support Inventory (ESSI [30]), a valid and reliable [31] seven-item scale that assesses multiple elements of social support. Higher scores represent greater levels of support (potential range 8–34).

Unsupportive social interactions were measured using an adapted version of the Unsupportive Social Interactions Inventory ([32]): designed to measure unsupportive or upsetting reactions from other people. It has 24 items and generates four subscales (distancing, bumbling, minimizing and blaming). Scores ranged from 0 to 4 with higher scores representing greater levels of unsupportive social interactions. The scale has been found to be internally reliable with a Cronbach's alpha of 0.86 [32]. In this sample, Cronbach's alpha was 0.89.

Perceived stigma was measured by the three-item felt stigma scale [33] that has evidence of internal reliability. Questions focused on whether the patient felt that others were (a) uncomfortable with them, (b) treated them as inferior, or (c) avoided them, because of their cancer. Higher scores represented a higher level of felt stigma.

Psychological distress was measured using the 14-item Hospital Anxiety and Depression Scale ([34]). This measure has proven reliability and validity and is in a variety of settings. Scores of 0–7 represent 'normal', 8–10 'mild', 11–14 'moderate', and 15–21 'severe' levels of anxiety or depression.

Dispositional openness was measured by a previously used single item, 'I am a person who usually talks to other people about my problems, concerns and daily life events' [2], and was rated on a six-point scale ('strongly disagree' to 'strongly agree') with higher scores indicating a greater degree of openness.

Clinical and socio-demographic data

Socio-demographic and disease-related information that was collected included age, gender, ethnicity, education level achieved, marital status, living arrangements, employment status, time since diagnosis, cancer type, treatment type, whether the cancer was visible ('Is your cancer visible, or does the treatment you received for it, make it visible to a stranger?') and whether anyone else was present when they received their diagnosis of cancer.

Statistical analyses

Analyses of variance (ANOVAs) were used to determine differences in disclosure between patients with different cancer types. Mann–Whitney U tests were used to determine gender differences in disclosure. Spearman's rho calculations were used to investigate which of the variables were associated with disclosure. The primary outcome variable of disclosure was represented by the mean level of disclosure for each participant. For the mean level of disclosure, the distribution was found to be normal (Kolmogorov–Smirnov Lilliefors, D(111) = 0.07, p > 0.05). Only variables found to be associated with disclosure in the correlational analyses were entered into the hierarchical linear regression analysis. A mixture of parametric and non-parametric tests was used according to whether the variables being investigated met the assumptions of a normal distribution.

Results

Of the 207 possible participants, 121 participants returned the questionnaire (59% response rate overall). The sample comprised of 45 with lung cancer (60% response rate), 54 with colorectal cancer (62% response rate) and 22 with skin cancer (49% response rate). One participant with colorectal cancer was subsequently excluded from the analysis as the majority of the questionnaire data was incomplete. The average age of the participants was 64 years (SD = 12 years, range 29–86 years). Refer to Table 1 for additional sample characteristics. In terms of the psychosocial measures, the sample reported high levels of perceived social support, low levels of unsupportive social interactions and low levels of stigma and distress, and the majority reported high levels of dispositional openness (Table 2). Scores on these psychosocial measures did not differ between patients with different cancer types.

Disease disclosure

The majority of patients disclosed information to a range of social targets, (mean = 7 different types of social target, SD = 2.0). The mean level of disclosure across all social targets was 2.71 (SD = 0.64). This represents the primary outcome variable of disclosure.

When the subgroups of potential disclosure targets were aggregated into mutually exclusive categories of family, friends and medical personnel, as seen in Table 3, little or no disclosure was reported by 21% to family members, 27% to medical personnel, and 43% to friends. Participants (7%) reported little or no disclosure beyond medical personnel and 11% reported little or no disclosure beyond their doctor and spouse. The degree of disclosure was fairly consistent across disclosure categories, with higher levels of disclosure reported to medical personnel (mean = 3.07, SD=0.81), followed by family (mean=2.83, SD=0.82), and friends (mean=2.39, SD=0.86).

Table 1. Clinical and demographic characteristics of the sample

	N	Per cent
Gender		
Males	75	63
Females	45	37
Ethnicity ($n = 118$)		
Black	8	7
Asian	4	3
White	103	87
Other	3	3
Highest level of education $(n = 118)$		
No academic qualifications	37	31
General Certificate of Secondary Education/A-level/Equivalent	38	32
Degree level or higher	29	25
Other	14	12
Relationship status		
Single	39	32
Married/Living with partner	81	68
Living arrangements		
Single occupancy	32	27
Living with others	88	73
Employment status $(n = 119)$		
Unemployed	8	7
Employed	27	22
Homemaker	3	3
Long-term sick	9	8
Retired	68	57
Other	4	3
Cancer type		
Skin	22	18
Lung	45	38
Colorectal	53	44
Time since diagnosis $(n = 119)$		
Within I year	54	45
I–2 years	65	55
First treatment $(n = 119)$		
Radiotherapy	3	3
Chemotherapy	9	8
Surgery	97	81
Other	10	8
Cancer visible $(n = 118)$		
Yes	20	17
No	98	83
Diagnosis received in company of another $(n = 119)$	70	
Yes	78	66
No	41	34

 Table 2. Psychosocial characteristics of the sample

		Potential	
	Mean (SD)	range	Cronbach's α
Perceived social support (ESSI)	28.68 (6.42)	8–34	0.927
Unsupportive Social Interactions	Inventory		
Distancing	0.48 (0.63)	0-4	
Bumbling	0.91 (0.78)	0-4	
Minimising	0.91 (0.83)	0-4	
Blaming	0.35 (0.51)	0-4	
Total score	0.66 (0.56)	0-4	0.894
Perceived stigma	0.35 (0.72)	0-3	(KR-20) 0.652
Hospital Anxiety and Depression	Scale		
Anxiety	6.51 (4.30)	0-21	0.861
Depression	4.29 (3.90)	0-21	0.872
Dispositional openness	3.88 (1.63)	1–6	_

The overall degree of disclosure did not differ between patients with different cancer types (F(2,108)=0.856, p=0.43). Furthermore, patterns of disclosure were not significantly different between patients with different cancer types (Table 4), with the exception of the level of disclosure to nurses (F(2,114)=3.307, p<0.05) and the level of disclosure to other patients with cancer (F(2,116)=7.607, p<0.01). Post hoc analyses indicated that patients with colorectal cancer reported a higher degree of disclosure to both nurses and other patients with cancer as compared with those with skin cancer (nurses, t(72)=2.168, p<0.05; other patients with cancer, t(94)=2.112, p<0.05); other patients with cancer, t(95)=3.695, p<0.001).

There were some differences in the patterns of disclosure between men and women. Compared with women, male patients reported a higher degree of disclosure to their spouse or romantic partner (U=1331.5, z=-2.11, p<0.05), colleagues (U=1233.5, z=-2.52, p<0.05) and to doctors (U=1071.5, z=-3.02, p<0.01) yet a similar level of disclosures across all other types of social target.

Factors associated with disease disclosure

Degree of disclosure was significantly correlated with higher levels of perceived social support (rho = .163, p < 0.05) and greater levels of dispositional openness (rho = .270, p < 0.01). None of the other demographic and disease-related variables (including ethnicity, age, gender, education, living arrangements, employment status, time since diagnosis, and whether the person had company whilst receiving the diagnosis) was associated with the degree of disclosure. However, the mean level of disclosure differed significantly according to treatment type. Patients who underwent surgery reported less disclosure (mean = 2.6, SD = 0.07) than patients who received chemotherapy ((mean = 3.1, SD = 0.17); [U = 193.00; z = -2.168, p < 0.05]) or 'other' treatments (mean = 3.1, SD = 0.17), [U = 246.50; z = -2.340, p < 0.05].

In the linear regression analyses, treatment type was entered at block 1, explaining 6% of the variance in disclosure (F(1,107)=8.303, p<0.01). Social support and dispositional openness were entered in the second block, and variance explained by the model increased to 13% (F(3,105)=6.387, p<0.01). Treatment type (B=-.240, p<0.01) and dispositional openness (B=.233, p<0.05) were statistically significant independent predictors of degree of disclosure.

Helpfulness of disease disclosure

The majority of participants rated disclosure as being helpful overall (mean = 4.09, SD = 0.97). The thematic analysis of reasons as to why disclosure was helpful (answered by 109 (91%) participants) indicated that disclosure 'helps gain reassurance and support' (n = 46, 38%),

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Table 3. Percentages and mean degree of disclosure

	Degree of disclosure (%)				Disclosure score	
	'Did not talk at all'a	Talked 'a little'	Talked 'somewhat'	Talked 'very much'	Mean	SD
Disclosure category						
Family members $(n = 103)$	7	14	13	24	2.83	0.82
Medical personnel ($n = 114$)	5	22	32	38	3.07	0.81
Friends $(n = 116)$	11	27	21	12	2.39	0.86
Overall disclosure across categories	2.71	0.64				

^aIncludes categories 'did not have the opportunity to talk' and 'purposefully chose not to talk'.

Table 4. Comparisons of level of disclosure for different social targets between patients with different cancer types

	d	ANOVA		
Type of social target	Skin	Colorectal	Lung	F
Spouse or romantic partner	3.16 (1.2)	3.06 (1.2)	2.95 (1.3)	0.42
Colleagues	2.11 (1.2)	1.94 (1.1)	1.63 (1.0)	1.93
Doctors	2.74 (1.0)	3.15 (0.9)	3.18 (1.0)	1.93
Nurses	2.63 (1.0)	3.17 (0.9)	2.75 (1.0)	3.31*
Siblings	2.26 (1.2)	2.37 (1.1)	2.30 (1.3)	0.01
Professional therapist/Counsellor	1.21 (0.5)	1.63 (1.1)	1.28 (0.7)	2.30
Friends/neighbours	2.47 (0.8)	2.58 (1.0)	2.38 (1.0)	1.24
Other patients with cancer	1.70 (0.9)	2.19 (1.0)	1.55 (0.9)	7.61**
Minister/Rabbi/Pastoral counsellor	1.26 (0.8)	1.21 (0.6)	1.18 (0.7)	0.10
Mother	1.37 (0.8)	1.56 (1.0)	1.18 (0.6)	2.63
Father	1.42 (0.9)	1.38 (0.8)	1.05 (0.2)	3.14
Children	2.63 (1.2)	2.44 (1.2)	2.73 (1.3)	0.82

^{*}p < 0.05; **p < 0.01

'allows emotional expression—being cathartic, relieving fear and releasing internal pressure' (n=28, 26%), 'allows for giving information' (n=23, 21%); 'helps gain perspective' (n=20, 18%), 'allows for gaining information' (n=18; 17%), helps 'clarify thoughts and make sense of their circumstances (n=11, 10%), aids 'practical planning' (e.g. for the event of their death; n=9, 8%) and facilitates 'adjustment and acceptance' of the diagnosis (n=9, 8%).

Whilst many participants left the question blank, indicated that it was not applicable or noted that they did not find talking to others to be unhelpful, some patients (n=48, 40%) gave reasons as to how disclosure could be unhelpful. Disclosure was found to be unhelpful when 'people have poor understanding' (n=13, 11%). Some patients found disclosure to be 'personally upsetting' (n=11, 9%) or to 'stimulate unhelpful reactions' (n=10, 8%). Other patients noted that by disclosing their disease, they were 'fearful of being a burden' (n=8, 7%) and found that 'disclosure evokes pity' (n=7, 6%) or that by talking about cancer, they were raising a 'taboo subject' (n=5, 4%) or one that has too much uncertainty to have useful discussions (n=4, 3%).

Discussion

This study aimed to quantify the degree of disclosure across social targets, determine the factors associated with disclosure, and explore whether patients perceive disclosure to be helpful in a sample of patients with a range of cancer types and across both genders.

In line with previous quantitative research [2–4], this study found that the majority of patients do disclose information, at least to some degree, to a variety of social targets. However, 21-43% reported little or no disclosure to entire subgroups of their social network; 11% reported little or no disclosure beyond their doctor and spouse, which is largely consistent with previous research [3]. The finding that the mean level of disclosure was greatest to medical personnel lends further weight to research demonstrating that health care providers play an important role in the disclosure interactions of patients with cancer [3], but this should not be at the expense of disclosure to other social targets. The finding that high average levels of disclosure were reported to 'family' and 'friends' social subgroups expands the earlier work that has emphasised the importance of informal helpers and confidants [4].

The finding that dispositional openness predicts cancerrelated disclosure is consistent with early notions that disclosure extends from intrinsic characteristics of the individual [10]. However, disclosure predictions based on stable personality traits can be complicated by situational factors [35], and this is perhaps why treatment type was also found to play a role in this study. Those receiving treatment other than surgery disclosed information to a greater extent, and it may be that treatments such as chemotherapy and radiotherapy involve longer treatment schedules with multiple, regular appointments and potentially more visible side effects therefore necessitating greater levels of disclosure. Higher levels of disclosure were also associated with higher levels of social support, confirming suggestions that social support systems provide an important context for disclosure [2]. Given the cross-sectional design of this study, it is uncertain whether greater levels of support led to higher levels of disclosure or whether increased levels of disclosure mobilised social support.

This study has advanced previous work by including men and women with different cancer types. Results revealed subtle differences in the pattern of disclosure according to gender whereby, compared with women, men reported higher levels of disclosure to certain social targets (their spouse/partner, colleagues and doctors). This is in keeping with previous research in men with prostate cancer, which found that men disclose information to those in their immediate circle of trust and disclose information on a 'need to know' basis to others [36]. Given that there were similar levels of disclosure to other social targets, it is important to avoid stereotypes suggesting that women are more talkative than men [1]. There were no differences in disclosure according to cancer type, with the exception of patients with colorectal cancer who disclosed information more to nurses and other patients with cancer. It is unclear whether this group of patients have more opportunities to meet other patients with cancer or nurses, as part of the treatment or rehabilitation programme, or whether there is an element of colorectal cancer that lends itself to more disclosure to these social targets. Future research could investigate these possibilities.

Disclosure was helpful as it allowed for the gaining and sharing of information, practical planning and facilitated adjustment through emotional expression and clarification of thoughts and by providing opportunities to gain a wider perspective or reassurance. These themes are consistent with the social-cognitive processing model of emotional adjustment to cancer that asserts that talking to a supportive other helps promote cognitive processing through a variety of ways [37]. Patients in this sample valued talking as it allowed them to gain medical information about the disease. This may give further explanation for the high levels of talk to 'medical personnel' and suggests that it may be driven by the patients' desire to gain medical information and the value placed on the greater knowledge and information that are now available for the patient. The finding that 'emotional expression' was helpful is compatible with research in breast cancer that has linked emotional expression with better outcomes [38].

However, for some participants, talking was unhelpful. Talking could lead to a perception of being pitied by others [36], be personally upsetting, or place a perceived burden on others [1,36]. Furthermore, friends and family may have a poor understanding of cancer and respond in unhelpful ways [2], and the stigma associated with cancer

may mean that other people are unwilling to talk. In addition, uncertainty surrounding a diagnosis can make conversations difficult. Therefore, in some situations, disclosure may be unhelpful, and ultimately, the patient must weigh up the costs and benefits of disclosing [39].

The insights gained in this study should be considered alongside the limitations. Because of the cross-sectional design, conjectures about causation cannot be inferred. In addition, one of the inherent difficulties in disclosure research is bias that can be introduced by studies attracting more open individuals [1,3]. Furthermore, the 'medical personnel' category was comprised of 'doctors' and 'nurses'. Therefore, patients may have been referring to disclosures with oncology doctors who are likely to be prompting discussions around diagnosis. Medical personnel may be already aware of the patient's diagnosis, and this may be the reason for their visit, so disclosure does not seem relevant. Thus, it may be expected that there would be a higher level of disclosure to these professionals as part of the natural health care process. It will be important for future research to account for this by distinguishing between disclosures that are prompted versus self-initiated.

It would be helpful to combine quantitative and qualitative methodologies in future research to generate a richer understanding of disclosure patterns and the content of disclosures. Furthermore, it has been suggested that it is important to look more closely at the role of the confidant in predicting the consequences of disclosures [8] and the impact that talking has on the relationship and adjustment [18,24].

In sum, this study contributes to what is known about disclosure in cancer by confirming that high levels of disclosure are common and that on the whole, people find it helpful to talk about their cancer. Individual differences in openness, treatment type and social support are important factors to consider. Currently, there are no formal structures to support the disclosure process, meaning that patients are largely left alone to navigate their way through unchartered territory of disclosure. Regular contact with the patient at clinic appointments means that health care professionals are well placed to support the ongoing disclosure process by opening up opportunities for discussion. Ultimately, a detailed knowledge of how people go about disclosure would inform strategies for supporting the process, minimise unhelpful disclosures and lead to an improved experience of care for the patient.

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