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SHORT COMMUNICATION

Routine assessment of social difficulties in cancer patients: are we opening Pandora's box?

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Abstract

Goals of work Living with cancer impacts on the social aspects of the lives of the patient and their families, causing problems that can remain undetected. The Social Difficulties Inventory (SDI) has been shown as an effective screening tool, but concerns exist that detecting more problems may increase the workload for clinic staff and related services. The aim of this analysis is to assess the level of unmet need for social difficulties and to identify any potential increase in required interventions that may occur as a result of detailed assessment.

Patients and methods A previous cross-sectional interview study was conducted to establish the clinical utility of the SDI. Adult patients were recruited from oncology, haematology and chest medicine clinics. They completed the SDI and a semi-structured interview by a social worker, who was blind to the SDI results. With participant agreement, interventions were made for the detected problems. This paper reports on a secondary descriptive analysis of intervention data, which was performed to examine the details of the interventions and referral patterns.

Main results No intervention was necessary for 108 (59%) of patients, 42 (23%) received information, 33 (15%) were referred to another service and five (3%) received both information and a referral. Most information was provided about holiday insurance. The majority of referrals were made to Social Work (55% of all referrals) with the main reason being related to benefits or finances.

Conclusions Increased referral rate was observed following a social work interview, when comparing with local audit data. However, the majority of needs could be met by increasing accessibility of information.

Keywords Cancer · Social difficulties ·
Patient-centred assessment · Psychosocial · Referral rates

Introduction

Various aspects of life may be affected by a diagnosis of and treatment for cancer. They may include home life, financial matters, relationships with others and recreational activities and hobbies, amongst others [1, 14]. Problems occurring in such areas of day to day life may be referred to as social difficulties, a broad definition driven by what patients report as their everyday issues [11]. These issues may be dealt with by accessing existing support networks [2], but for some this may not be available, or the severity of the problem may require professional assistance [14]. These problems may cause psychological distress and affect the well-being of the patient, but they may go undetected by clinical staff [1, 10] perhaps because it is not possible to identify at-risk patients clinically or by observing socio-demographic status [13]. Patients may not raise such issues with clinic staff. Discussion may be restricted by time limitations, pre-conceived ideas about what constitutes 'normal' clinical discussion and concerns from staff about raising complex issues that may not be easily dealt with in the outpatient setting. Even skilled communicators may

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find some areas difficult to address, such as patients' relationship with family members [9].

Social problems have the potential to affect levels of distress, anxiety and other psychological morbidity [1], and the need to deal with such issues is widely recognised [3–5]. In a patient consultation exercise carried out by Macmillan Cancer Support, the theme 'Impact on Life' was identified as the top priority for research [4]. Previous work by this group has sought to identify specifically what these social problems are [11] and develop a tool to aid their recognition within the oncology population [10]. This work has resulted in the development of the Social Difficulties Inventory (SDI). The SDI identifies 21 key areas or items in which a patient may self-report the level of difficulty experienced, ranging from 'no difficulty' to 'very much difficulty' (see Appendix A). The SDI has been psychometrically tested and proven to be suitable to detect social difficulties in oncology practice. It has been demonstrated as a clinically useful, relevant and well-accepted instrument [10]. The SDI will complement other instruments that address these and other domains, e.g. physical functioning and emotional distress. The questionnaire may be administered within a clinic, with touchscreen technology providing real-time results. Work is ongoing to develop staff guidance on using the SDI before it is routinely employed [10, 12, 14].

Despite the requirement for such a tool and evidence of its effectiveness, there is a concern that using the SDI may increase time spent on bureaucracy and offering advice. It could potentially generate extra referrals to supportive services, resulting in unmanageable workload increases. This impact should be carefully considered, as oncology staff already report higher rates of burnout than their colleagues in other specialties [6, 7]. However, assessment tools such as the SDI also have the potential to facilitate better doctor–patient communications, leading to improved relationships and patient satisfaction [8]. This in turn can lead to improved job satisfaction, which has a protective effect on the mental health of oncology staff [6, 7]. From a service delivery perspective, it is therefore important to try and estimate the extra workload and interventions that screening with the SDI may generate. There is unfortunately a lack of comparable data on existing referral patterns on which to base this estimate. There is only historical local audit data available from 2006. This reports on referrals in standard practice, from a dedicated radiotherapy unit (Cookridge Hospital) to local support services. Referral rates from outpatient clinics to the on-site social work team were 3.2%. The referral rate from the Leeds Cancer Centre to psychosocial services (clinical and health psychiatry and liaison psychiatry) was 1.5% [14].

A cross-sectional study was conducted to establish the clinical meaning and utility of the SDI (reported elsewhere). During this study, participants were asked to complete the SDI, then take part in an interview with a social work researcher, who was blind to their responses on the SDI. Following these interviews, the researcher made interventions for 41% of participants. Brief counts of the interventions made were originally reported in order to validate the cut-off score identified for the SDI and to feed into early development on guidelines on its use [14]. In order to assess the level of unmet need and identify any potential increase in interventions required from such routine, detailed assessment of social difficulties, a secondary descriptive analysis of intervention data is reported here.

Patients and methods

Original cross-sectional study

Following the approval by a local ethics committee, patients were recruited to a cross-sectional interview study. Adult patients who could read English, had the capacity to complete the questionnaire by touchscreen computer and who were not already participating in other psychosocial oncology studies were accessed from outpatient clinics or day units in oncology, haematology and chest medicine. All provided written informed consent. Socio-demographic and clinical data were collected from the patient or their medical records.

Patients completed the SDI and were interviewed at home within 1 week by a social work investigator (PW), who was blind to the SDI results. This was done to ensure unbiased comparisons between the patients' self-reported SDI scores and the scores attributed to each of their difficulties by PW following the interview. The aim was to examine the clinical meaning and utility of the SDI. The interview was semi-structured, audio-recorded and included an overview of their experience, followed by detailed questioning on the impact of the diagnosis on their everyday lives.

On completing the interview, items raised as a concern were discussed further. Where a need was identified and on agreement with the patient, provision of information or one or more formal referral/s were arranged, in some cases both. Post-interview reports were made, which recorded details of the interventions made and the reasons behind them. Full details on the methods employed are reported elsewhere [14].

Secondary analysis reported here

Socio-demographic data and post-interview reports were obtained for each participant. Data were extracted from the reports to note if an intervention had been made and if so, the nature of the intervention (information provision, referral to another service or both). Services to which people were referred and the topic of information provided were recorded. The reasons for intervention in all cases were also recorded where known.

Analyses

Descriptive analyses on the socio-demographic and clinical data and the number and nature of interventions had been completed as part of the original study [14]. Counts were taken of the number of participants receiving an intervention, the nature of the intervention, the service to which referrals were made and the subject of information provided. Reasons for intervention were categorised according to the most common themes, based on the items from the SDI (Appendix A). Categories include benefits or finance, communication difficulties, body image, sexual difficulties, requirement for disabled parking (blue badge) and isolation. Combinations of reasons were recorded where appropriate. Where the participant required general support for an unspecific issue, this was categorised as 'uncertainty and adjustment' issues, which relates to matters around adjusting to the impact of the diagnosis and general coping. Counts were taken of the categories of reasons for intervention.

Results

Participants

Overall, 273 patients were approached, of whom 191 consented and participated in the study (70%). Two participants failed to complete the SDI, and six patients dropped out before the interview, leaving 183 patients who participated in full. Socio-demographic and clinical details of the participants are presented in Table 1.

Types of and frequency of interventions

Interventions were classified as information provision, referral to another service or both. Figure 1a demonstrates frequency of interventions, including topic of information provided and reasons for referral. Fifty-nine percent of patients required no intervention (n=108), and 23% (n=42) received information, including advice on or contact details for services. Fifteen percent of patients were referred (n=28 with three referrals offered but refused), and 3% received both information and referral. Including the five patients that received both interventions, 36 referrals were made for 33 patients, with three participants being referred to two services. Overall referral rate, including cases where both interventions were provided, was 18%.

Of all referrals made, 55% were to social work (11% overall). In three cases, this was made in combination with another service (dietician, support group and psychological services). Forty-nine reasons were cited for the 36 referrals. The most common reason for referral was to discuss welfare benefits and/or finances (42%). Of all referrals for benefits, 80% were to social worker, with others to a Macmillan nurse and a Clinical Nurse Specialist (CNS). Other referrals to the CNS were made for a combination of communication difficulties, body image and uncertainty and adjustment (n=1) and sexual difficulties (n=1). Uncertainty and adjustment issues were cited as the reason for referral in 14% (n=7) of all referrals, but in six of these cases, this was listed as one of a combination of reasons.

Including the five patients who received both interventions, 47 patients were provided with 67 'items' of information in total (26% of participants). The areas for which information was most commonly provided were holidays (27%), support centres or groups and benefits and finance (13% each) and social work (10%). Of the information provided around holidays, the vast majority was relating to holiday insurance (n=12/14). Information on benefits was general advice on what people may be entitled to and how to access the appropriate service. Similarly, Social Work information consisted of contact details to allow self referral, and general advice on what the service could assist with. 'Other' areas of information included careers service, complementary therapist, contacting the CNS and advice regarding a water meter. Figure 1b demonstrates the relationship between the service to which patients were referred and the reason for which the referral was required.

Discussion

When patients routinely attending outpatient clinics had a formal interview with a social work researcher, approximately 40% required intervention for social difficulties. However, in around half of these cases, only information was required. Referrals to social work accounted for over half of the overall referral rate to other services (18%).

The majority of referrals were made to social work for benefits information. Other referrals for finances were made to cancer support centres, Macmillan Nurses and a CNS. The next most common reasons for referral were uncertainty and adjustment issues (n=8). Half of these were to social work, three to psychological services and one to a CNS. Applications for the disabled badge parking scheme accounted for 10% of referrals. Social work was also involved in three of five referrals made for body image issues.

The majority of information provided was in the context of 'signposting' patients in the direction of the appropriate

Table 1 Socio-demographic and clinical data of participants (n=183)

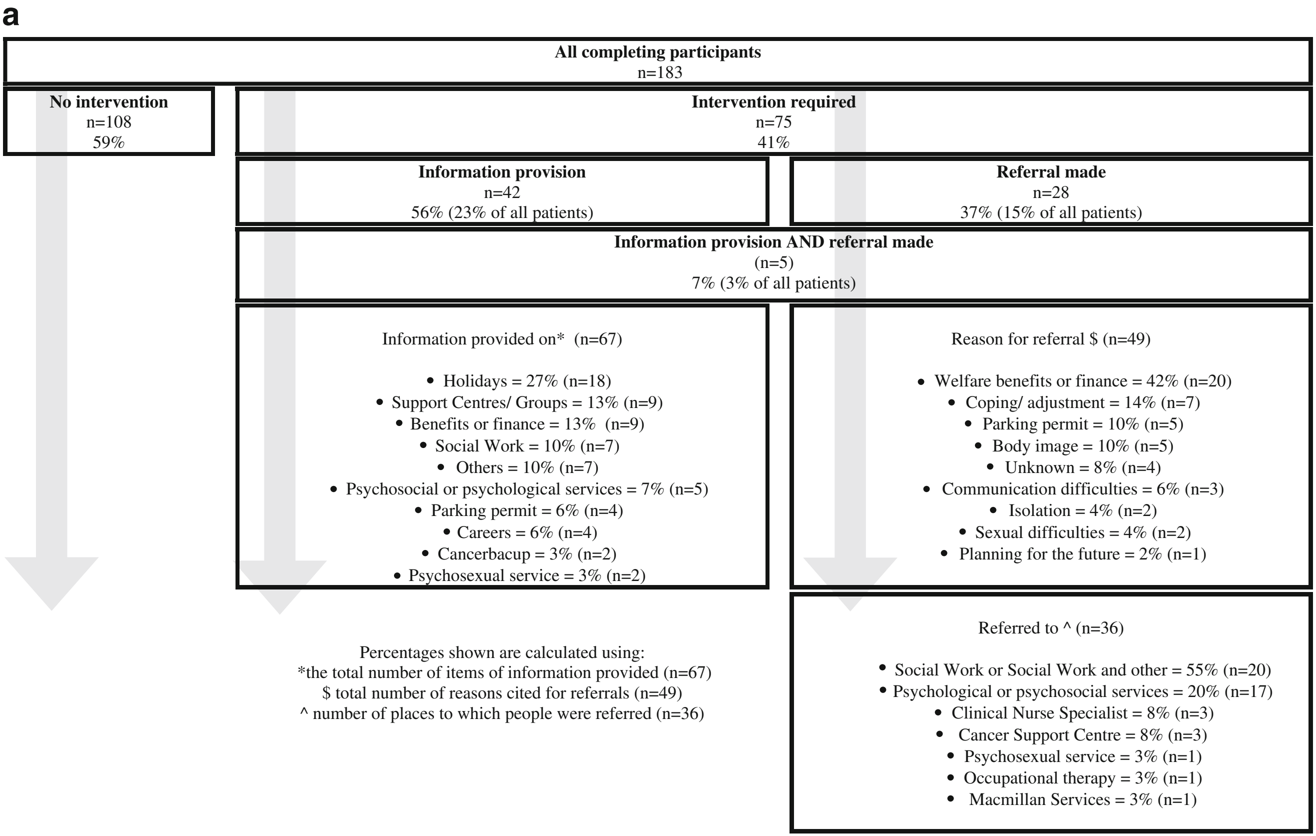
		Samples	Percentage
Socio-demographic			
Gender	Male (median age 60 years, range 18 to 88)	98	54
	Female (median age 54 years, range 23 to 87)	85	46
Marital status	Single	18	10
	Married or cohabiting	136	74
	Separated or divorced	16	9
	Widowed	13	7
Who do you live with	Wife, husband or partner	88	48
	Child(ren)	11	6
	Parent(s) and/or other relatives	8	4
	Other relatives	2	1
	Friend(s)	1	0.5
	Alone	23	13
	Other	1	0.5
	Partner and child(ren) and/or other relatives	47	26
	Partner and other	1	0.5
	Not stated	1	0.5
Accommodation	Owner–occupier	143	78
	Renting privately	10	5
	Renting from council	23	13
	Other	7	4
Occupational status	Full time employment	75	41
	Unemployed	19	10
	Student	2	1
	Retired	74	41
	Homemaker	6	3
	Other	7	4
Working hours	Working same hours	29	16
	Working less hours	18	10
	Not working	132	72
	Working more hours	4	2
Education	Compulsory education	136	74
	College or professional qualification	44	24
	University	3	2
Ethnic origin	White	173	94.5
	Black Caribbean	1	0.5
	Black African	2	1
	Not disclosed	7	4
Clinical			
Diagnosis	Head and neck (inc brain)	12	6.5
	Lung	24	13
	Genito-urinary	14	8
	Germ cell	12	7
	Haematological	21	11.5
	Gastro-intestinal	37	20
	Breast	27	15
	Gynae	19	10
	Sarcoma	7	4
	Melanoma	10	5

Table 1 (continued)

		Samples	Percentage
Extent of disease	Disease free	60	33
	Primary local	34	18
	Local recurrent	5	3
	Metastatic	61	33
	Other	23	13

service, e.g. providing a list of contact details for specialist insurance companies. Other information commonly provided in this way was on contacting support groups/centres and benefits. Only 14% of information provided was noted as being on more miscellaneous subjects that may not be readily linked to an existing service.

The findings and recommendations made in key guidance documents [3–5] are mirrored in this analysis,



b

	Service						
Reason for referral	Social Work or Social Work and other	Psychological or psychosocial services	Clinical Nurse Specialist	Cancer Support Centre	Psychosexual service	Occupational therapy	Macmillan Services
Welfare benefits or finance	n=16		n=1	n=2			n=1
Coping/ adjustment	n=2	n=4	n=1				
Parking permit	n=5						
Body image	n=3	n=1	n=1				
Unknown	n=1	n=2				n=1	
Communication difficulties	n=1	n=1	n=1				
Isolation	n=1	n=1					
Sexual difficulties			n=1		n=1		
Planning for the future	n=1						

Fig. 1 **a** Type, frequency and details of interventions, **b** reasons for referral by service

suggesting that identification of social difficulties in routine care may still be limited, with 41% of patients still living with unresolved issues at the time of participation. In around half of these cases, increased accessibility of information may have avoided the problems with which patients presented. When considering the reasons for referral, this is again highlighted. For example, provision of a leaflet on benefits and disabled parking could potentially reduce referrals. This has implications for staff training. Whether identification of social difficulties happens through formal channels or through informal discussion in the waiting room, it is important that the staff know how to advise patients once an issue is raised. Consideration of these factors in implementing an assessment would help to optimise use of staff and patient resources and minimise the impact on workload and services.

During this study, difficulties were assessed in a rigorous way by discussion with an experienced researcher, trained in medical social work. The discussion may have identified more problems than can be expected in routine clinical practice. Although work is ongoing to determine the best application of the SDI in this setting, it is unrealistic to expect that each patient would go through such a detailed process.

This report demonstrates a referral rate to social work of 11%, which is higher than that reported locally (Cookridge Hospital—3.2%), perhaps reflecting the experience and background of the researcher and the rigorous data collection in a research project. Similarly, a 13% increase in referrals to psychosocial services (clinical and health psychology and liaison psychiatry) is also demonstrated, up from 1.5% in the local historical data (Leeds Cancer Centre) to 20% in this analysis. This suggests large increases in workload. However, providing effective information on services may potentially have reduced this figure by around 3% for social work and 13% for psychosocial services, if information was accessible to patients on services they could access themselves, e.g. accessing support groups for body image issues or information on disabled parking permits. Coping and adjustment issues are more likely to be complex needs, requiring intervention over and above information provision, and therefore, these have not been included in this estimated reduction. The researcher's knowledge of patient eligibility and available resources resulted in referral where there was no specific difficulty, but the patient was unaware of an entitlement to benefit. This again highlights the importance of good signposting and accessibility of information.

Throughout this report, an assumption has been made that referral to another service would be the most time consuming of the interventions. Specific timescales may depend on a variety of factors, e.g. the knowledge base of the referrer, the service to which the referral is being made (i.e. their processes and availability) and the lines of communication between the two. Information provision should be the least time consuming, but is dependent on the nature of the problem and the type and availability of information.

Further research is planned by this group to assess the impact of information provision to patients on referral rates, communication on these issues during clinician contact, process of care and patient outcome measures. The availability and processes of information provision are subject to variability between sites and health care service providers. Oncology care providers may wish to consider replicating such research in their own unique settings to serve their patient populations effectively. The level of unmet need found in a population served by a large dedicated cancer centre could be used in presenting a case for funding for such further research.

In conclusion, in-depth assessment of social difficulties appears to increase referrals, but increased availability and accessibility of relevant, high-quality information for patients could reduce the need for interventions. The information required could be made available as leaflets or other resources that patients can access in the waiting room.

Implementation of the SDI by trained staff has the potential to increase the frequency with which social problems are identified and dealt with, fulfilling the requirements of the Cancer Reform Strategy [3].

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Disclosures None.

Appendix A: The Social Difficulties Inventory

Sometimes people who have, or have had cancer find that they have a number of everyday difficulties to cope with following their diagnosis. These may be to do with things like their family life, social activities, finances and work.

We are interested in finding out what difficulties and problems patients have to cope with. Only when we find out the range and depth of these difficulties can we begin to make plans for giving support to patients who may need it.

- Please read each question carefully and tick the response that best describes your answer
- Please answer each question as honestly as possible
- If you are not completely sure which response is the most accurate tick the box that you feel is the most appropriate
- Please tick the 'no difficulty box' if a question does not apply to you
- Do not spend long on each statement

	During the past month:	No difficulty	A little difficulty	Quite a bit of difficulty	Very much difficulty
1	Have you had any difficulty maintaining your independence?	☐	☐	☐	☐
2	Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	☐	☐	☐	☐
3	Have you had any difficulty with managing your own personal care? (e.g. bathing, dressing, washing)	☐	☐	☐	☐
4	Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)	☐	☐	☐	☐
5	Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	☐	☐	☐	☐
6	Have you had any difficulties with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)	☐	☐	☐	☐
7	Have you had any financial difficulties?	☐	☐	☐	☐
8	Have you had any difficulties with financial services? (e.g. loans, mortgages, pensions, insurance)	☐	☐	☐	☐
9	Have you had any difficulty concerning your work? (or education if you are a student)	☐	☐	☐	☐
10	Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs)	☐	☐	☐	☐
11	Have you had any difficulty communicating with those closest to you? (e.g. partner, children, parents)	☐	☐	☐	☐
12	Have you had difficulty communicating with others? (e.g. friends, neighbours, colleagues, dates)	☐	☐	☐	☐
13	Have you had any difficulty concerning sexual matters?	☐	☐	☐	☐
14	Have you had any difficulty concerning plans to have a family?	☐	☐	☐	☐
15	Have you had any difficulty concerning your appearance or body image?	☐	☐	☐	☐
16	Have you felt isolated?	☐	☐	☐	☐

17	Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	☐	☐	☐	☐
18	Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)	☐	☐	☐	☐
19	Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits)	☐	☐	☐	☐
20	Have you had any difficulty with your plans to travel or take a holiday?	☐	☐	☐	☐
21	Have you had any difficulty with any other area of your everyday life?	☐	☐	☐	☐

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