

Abstract

Objective

‘Improving the Cancer Journey’ (ICJ) is an original, community based, multidisciplinary service offering holistic support to people diagnosed with cancer in Scotland. It is the first service of its kind in the UK. The aim of this qualitative study was to explore the experiences of people who have used this service.

Method

Twenty service users were purposively sampled to capture a diverse range of age, sex, cancer types, and deprivation status. Semi-structured interviews explored their experiences of using ICJ. Interviews were transcribed verbatim and thematically analysed.

Results

Thirteen females and seven males (mean age 58 years) were interviewed. Three themes were identified: ‘one person, one place’, ‘routes to unexpected support’, and ‘safety net’.

Conclusion

ICJ was perceived to be beneficial because it met the holistic needs of the ICJ service users. By helping people address concerns earlier rather than later, it prevented problems becoming unmanageable. Having an accessible expert to guide and support them through a range of services provided reassurance and created the space to self-manage at a time of distress. These original findings are internationally relevant because there is little evidence on the impact of holistic support services from the patient perspective.

INTRODUCTION

International guidance on supportive cancer care states that assessment and discussion of patients' and their family's needs for physical, psychological, social, spiritual and financial support should be undertaken routinely in order to provide person centred care (National Institute for Clinical Excellence, 2004; Holland *et al.* 2011; NCCN, 2017). Psycho-oncology programmes have historically taken the lead here and focused on screening for distress (Bultz *et al.* 2011; Carlson *et al.* 2003; Holland *et al.* 2007). A common approach is to screen new patients with the Distress Thermometer (DT) and associated Problem List (PL). In the United Kingdom (UK), the term 'Holistic Needs Assessment' (HNA) is used to describe a comparable approach to care. In summary, HNA is promoted as a way of ensuring that an individual's needs are met through discussion and the development of a care plan (Mitchell *et al.* 2018).

There is widespread recognition of the need to identify the negative impact of cancer on patient well-being (Donovan, Grassi, McGinty, & Jacobsen, (2014). Identifying what needs are important for the patient can inform service planning (Mitchell *et al.* 2018). What is more, addressing patient concerns and distress can reduce unmet needs, facilitate self-management enhance patient/practitioner communication and improve cancer outcomes (Watson *et al.* 2016; Doyle & Henry 2014; Mitchell, 2013; Carlson *et al.* 2012; Piri *et al.* 2012). However, the capacity to deliver such programmes is often a challenge. Psychosocial services may be understaffed or underfunded and clinician reported barriers include a lack of time, resources and training (Groff *et al.* 2018; Wells *et al.* 2015; Hawkes *et al.*, 2010). This is despite the observation that very few people found to be distressed subsequently go on to attend an appointment with a psychologist (Carlson *et al.* 2013; Snowden *et al.*, 2012). There is stigma attached to accessing psychological services (Gunn *et al.* 2013), but people may also decline

these appointments as they do not perceive their distress as being psychological. Distress is a multifaceted concept and referral to psychological services alone does not cover other issues relating to, for example, practical problems that people may have (Delgado-Guay *et al.* 2015; Carlson *et al.*, 2010).

Improving the Cancer Journey

As an alternative or adjunct to distress screening, patient navigators have been deployed to identify unmet needs for people affected by cancer (Manderson, McMurray, & Piraino, 2012; Wood, Sellers, Shea, & Mayer, 2017). Predominately used in the U.S and Australia, patient navigation programmes support and guide cancer patients and their families through the cancer care system in a seamless and coordinated manner (Freund *et al.*, 2008). Examples of navigation can include signposting to financial support, linking to community resources and providing emotional support (Freund *et al.*, 2008; Wood *et al.*, 2017). The model developed from the acknowledgement that people diagnosed with cancer need more than medical and psychological support alone.

It was against this background that the service ‘Improving the Cancer Journey’ (ICJ) was developed in the UK. ICJ is a community-based service supporting people affected by cancer in Glasgow, Scotland. It is managed by the city council (the administrative body that governs the city) and the local National Health Service board is a key partner alongside a major UK cancer charity, Social Work Services and various services and non-governmental organisations located across health, social care and the third sector. Hence, it is an integrated service operating across several different care providers. This service is novel for three reasons. Firstly, it is proactive and inclusive; every person in Glasgow City Council area with a new diagnosis of cancer is sent a letter from ICJ offering their assistance. Secondly, the key

intervention (HNA) is facilitated by a 'link officer'; a trained council employee, not a nurse or health service professional as is usually the case. Thirdly, whereas most assessments pertaining to cancer are delivered in a health setting, such as an outpatient clinic, ICJ supports the person at a place of their choice, which is usually their home.

Typically, the initial visit lasts one hour, during which time a care plan is co-constructed between the patient and link officer, designed to detail actions for supporting the concerns. Often the plan takes the form of signposting to a particular agency, or referral to relevant services. All referrals are managed by the link officers. After the visit, the patient receives a letter from ICJ detailing the agreed care plan and a summary of the discussion. Individuals are then reviewed, anytime from about two weeks to five months later depending on the ease with which any raised concerns can be addressed, patient preference and prognosis. This review usually occurs over the telephone.

ICJ has parallels with the navigation approach in that a named person (the link officer) actively seeks to support people living with cancer and meet their needs by signposting or providing onward referrals. In navigation programmes navigators are usually classed as 'professional' (e.g. social workers and nurses) or 'lay health workers' (no formal certified or degree education in a health or related field) (Shelton *et al.* 2001). Where ICJ differs, is that the link officers are employees of Glasgow City Council with professional backgrounds in housing, financial inclusion, home care and social care. In addition, they have, or are working towards being accredited with a level 3 Scottish Vocational Qualification (SVQ) in healthcare support to reflect their competencies in this area. SVQ's are work based qualifications where learners gather evidence from their work to reflect their knowledge and skill. It is academically equivalent to graduate diploma level, or second year of baccalaureate degree. This is supplemented with a 3-month induction period, training and development by ICJ

partners and supervision with a clinical psychologist. Therefore, they are not health or social work ‘professionals’ but they are equipped with the appropriate knowledge to support the non-clinical needs of the cancer population.

Since its launch in 2014 the service has supported over 4000 people and has made referrals to over 220 agencies for housing support, financial support, complementary therapies and exercise classes, amongst others. In addition, individuals are offered ‘self-management’ in the form of information booklets. There is a range of evidence supporting the positive impact of ICJ. For example, there is quantitative evidence of a reduction in overall concern score (elicited from the HNA) between the first visit from ICJ and the review (Snowden, Young and Savinc, 2018). In addition, ICJ was highlighted in the 2016 Scottish Government cancer strategy as an integrated model to replicate, with £9 million set aside for comparable projects (Scottish Government, 2016).

Despite this acclaim, the experience of using the service has not been studied in-depth. Addressing patient concerns can improve measurable outcomes such as well-being but less is known about the experiences and perceptions that underpin these improvements (Van Hoose *et al.* 2014). Given the unique attributes of this service, this research has sought to understand how and why this form of support may make a positive impact on the lives of people affected by cancer. Analysing the patient experience in depth here could help others understand what interventions may improve experiences for people affected by cancer in the future (Hibbard & Helen, 2014).

METHOD

This study is part of a longitudinal mixed methods project. A detailed protocol is published elsewhere (Snowden, Young, & Fleming, 2016). The longitudinal project uses a range of methods to understand the impact and process of ICJ from the perspective of: people affected by cancer who have used the service, the link officers and wider stakeholders from across health, social care and the third sector. Data gathering includes questionnaires, interviews, observations and reflective diaries. This paper focuses only on the interviews conducted with ICJ service users. Data collection and analysis for the other components of this study is still ongoing.

Design

Semi-structured interviews following Braun and Clarke's (2006) thematic analysis methodology. The Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines were used to report findings (Tong, Sainsbury, & Craig, 2007). The checklist is appended as a supplementary file.

Participants

Participants were individuals who had received support from ICJ. Therefore, all participants were currently living in the Scottish city Glasgow. Glasgow is Scotland's largest city with a population of approximately 600,000. Nearly half of Glasgow's population reside in 20% of the most deprived areas in Scotland (Scottish Government, 2012). In addition, in comparison to the rest of Scotland the greater Glasgow area has the highest cancer mortality (Information Services Division, 2018).

For most of the participants, support from ICJ consisted of an initial visit and then a follow up at a second time point ranging from one to five months later, depending on the ease with

which any raised concerns could be addressed and preference. Those who did not receive a follow up (n=3) had stated at the end of their first visit that they did not require any further support from the service as they had few concerns. Participants were recruited to this study by a postal survey administered by ICJ (on behalf of the research team) as part of the wider mixed methods study.

A final question in the survey asked the participant if they would be willing to take part in a face-to-face interview on their experiences of accessing support from ICJ. The questionnaire was sent to a random sample of 500 individuals who had used ICJ from 2015-2016. From 185 total responses (37% response rate), 45 agreed to an interview. From these, we purposively sampled 22 people. Sampling was based on sex, diagnosis, Scottish Index of Multiple Deprivation (SIMD) and age, in order to obtain as diverse a sample as possible. The rationale was to interview a heterogeneous sample to obtain a range of different viewpoints.

Procedure

Participants were approached by telephone or email (depending on their preference as stated in the survey). No one refused to take part. In two cases the interview was arranged but then cancelled due to illness and a family bereavement. Twenty face to face interviews were arranged at a time and in a location that was suitable for the participant. In most cases (n=16) this was the participant's home, followed by a library (n=3) and a café (n=1). In the majority of the interviews (n=18) no one else was present apart from the researcher and the participant. However, in one interview the participant's partner was present and in another interview the participant's child was present. Written informed consent was obtained from all participants. Interviews were conducted between December 2016 and May 2017 by one researcher (JY). A semi-structured interview schedule was designed to mirror the process of ICJ. That is, it

explored what participants were experiencing in relation to the following elements of ICJ: routes into the service, motivations for using the service, support needs and onward referrals. However, the schedule was used flexibly to allow the participants to describe their experiences of using the service in their own words. After completing the twentieth interview data saturation was reached (Charmaz, 2006). This was deemed to have occurred as no new themes were identified from the data (Thorne, 2011). The interviews were stopped at this point, as we did not feel it was necessary or ethical to approach anyone else for their participation.

Data analysis

All interviews were recorded and then transcribed verbatim by one member of the research team. The data were analyzed following Braun & Clarke's thematic analysis (Braun & Clarke, 2006). This involves identifying, analyzing and reporting patterns or themes across the dataset. We chose this inductive approach to the analysis rather than a theoretical one as the study was descriptive and exploratory (Braun & Clarke, 2006). Two researchers (JY and AS) read the transcripts and independently generated line by line codes, representing 'units of analysis'. They then met to discuss early interpretations and reconcile any differences. The researchers then constructed themes from the codes to create an accurate representation of the whole (Corbin, 2009). They cross-checked again to double check the codes accurately represented the data, and the grouping of codes within the themes was considered to be a good 'fit' (Lomborg & Kirkevold, 2003). See table 2 for themes and a representative sample of the line by line codes. The codes selected most accurately represent the themes.

RESULTS

Twenty people were interviewed. Interviews ranged from 32 minutes to 50 minutes (mean 38 (12) mins). All had used the service within the last 12 months. Demographic details are presented in table 1.

Table 1 Demographic characteristics of the participants here

Three overarching themes best accounted for the majority of the data. They were: ‘one person, one place’, ‘routes to unexpected support’, and ‘safety net’. Table 2 presents the themes and codes.

Table 2 Themes and codes here

Theme one: One person, one place

Participants valued having one point of contact to help them navigate through the cancer system. The link officer liaised with other professionals and assisted with tasks such as completing paperwork and making phone calls. This was valuable particularly within the early diagnosis and treatment phase, when they were too ill to do this themselves:

“At the time, I was struggling and everyone came out here. They filled out all the forms, they arranged everything, dealt with everything” [Interview 8, female]

The interviewees describe ICJ simplifying their lives by reducing many incomprehensible contacts located across the health and social care system down to an understandable and accessible one:

“I think it’s great how everyone is tied in with everyone else doing referrals. It saves you looking yourself and going online” [Interview 18, female]

That the support came to them in ‘one place’ rather than having to seek it out was a defining feature of their initial experience. It was contrasted with an unwelcome image of having to go to many places when at a low ebb:

“When you’re in that place you don’t have the energy either to think but it was just one place you had to go and they accessed everything for you, they accessed after chatting to you what they thought you needed rather than going to half a dozen different places which you don’t really have the energy for” [Interview 13, female]

I had a place to ask people. I could phone them up and say how do I deal with this concern. So, there’s a contact, there’s a place to go. To have that support is wonderful. [Interview 7, male]

Moreover, this pre-emptive approach to support was useful for those that lacked confidence.

The following quote suggests the interviewee may not have attended subsequent appointments without the support of ICJ:

“I don’t like approaching places. I would never have gone and got help myself, I never would’ve done that. So, I don’t know what I would’ve done actually if the service hadn’t been there” [Interview 8, female]

However, not everyone approached their care this way. ICJ did not have such a positive impact for two participants who were more informed or had other support networks:

“I actually phoned them up and told them exactly what I needed, I was quite specific. So he came out but he was just a sign-poster. So I said I don’t need that, no offence but if all you’re doing is signposting I may as well just go on the internet” [Interview 10, female]

“I can’t really remember them (ICJ) coming out as I don’t think I’m in need of any other help. My wife always attends any meetings I have with my consultant. There’s two charities available near me and my GP is very good” [Interview 4, male]

This theme captures the benefits when patients receive guidance and navigation through the cancer system. Without such a guide it seems unlikely that some of these participants may have sought out the support themselves due to a lack of energy and confidence. The importance of this becomes even more apparent in the next theme as people begin to realise

that some of their concerns are multifaceted – requiring support beyond the healthcare system.

Conversely, the guiding nature of ICJ was less welcome in a situation where someone had predetermined expectations as to what an ICJ visit may entail. For example, one participant (interview 10) seemed disappointed that the purpose of the assessment was ‘just signposting’. Confident she could find this information herself she appeared to want more immediate specialist support. Whilst a minority view it serves to highlight the importance of understanding expectations at the outset.

Theme two: Routes to unexpected support

Being newly diagnosed, most participants were unaware of the wider support available to them until ICJ informed them of it. Making reference to the HNA process this participant highlights how support was tailored to individual choice:

“You’ve never been in that situation, so you don’t know what’s available so it’s good to have someone to guide you. They asked lots of questions would you benefit from massages, walking groups, talking groups that kind of thing [Interview 13, female]

Critically, almost every participant interviewed stated they needed support with financial difficulties and this was having an adverse effect on their well-being. The participants described feeling worried and anxious as they realised that a cancer diagnosis can cause difficulties beyond their physical health:

“I was on no pay and I had a mortgage to pay. I think it can become a crisis when you’re ill and it can become a crisis not just because of your physical difficulties”. [Interview 10, Female]

“I was off work so it was difficult. Money was my main immediate worry. I knew it would be a while before I was back on my feet [Interview 12, Male]

Yet, they did not realise they were eligible for any support until informed by ICJ. As a result, ICJ helped to alleviate some of the burden associated with these financial concerns by making referrals or providing information on financial support:

“I was worried about money, I was worried about losing my home. I didn’t know there was so much help available. So that was a relief because there was benefits I was entitled to and I didn’t realise” [Interview 9, male]

Despite it being a significant concern it seems that some of the participants had not discussed their financial situation before because they felt the health setting was not an appropriate environment to raise non-medical concerns:

“My oncologist was very good and my surgeon was amazing but you’re only one of god knows how many people. So, I think it was good to have another outlet to ask questions and practical things too, you know” [Interview 13, female]

Financial difficulties can stem from changes in income and ‘out-of-pocket’ expenses due to lifestyle adjustments, such as using taxis more frequently or higher fuel bills. Participants had not expected any support with their financial concerns neither had they expected this form of support to be the remit of health practitioners. Therefore, they benefited from having an outlet to discuss financial, practical and lifestyle concerns:

“She was fantastic and that was the first time I had spoken to anybody who wasn’t medical. Her expertise wasn’t medically based but I found it really useful” [Interview 19, female]

In interview 19, this was deemed to be particularly useful as it was the first time she had spoken to someone who was not a medical professional. Consequently, this generated a new appreciation for professionals with expertise in non-clinical matters who can also provide valuable support.

Theme three: Safety net

Typically, interaction with ICJ involves one or two face-to-face visits and a telephone review. Nevertheless, ICJ was experienced as a *constant* source of support. This was described by one participant as a ‘safety net’:

“It’s a safety net that’s there; if it’s taken away, don’t ever get it taken away”
[Interview 1, male]

This feeling appears to stem from knowing exactly where to access ICJ again should the support be required in the future. Having this safety net in place provided reassurance and a feeling of connection:

“I have the phone numbers and I sometimes pop in so it’s not cut off completely”
[Interview 6, female]

“I really count on them I know anytime if I need to share something I know they will listen” [Interview 3, female]

The participants’ language infers they feel a familiarity with the service. That the service will ‘listen’ and can be accessed easily is more characteristic of say a friend than a cancer service. Knowing the service is there, ready to respond with support should it be needed, appears to provide comfort and strength and encourage self-management:

“I’m going for major surgery soon but it’s ok I know I’ve got the help there if I need it. If anything crops up I can pick up the phone” [Interview 9, male]

“Having the service there I knew there was someone just a phone call away that makes a big difference. Then it encouraged me to do more research on my own. I was looking at the work situation it encouraged me to do a lot of things on my own”
[Interview 19, female].

However, not everyone expressed such a deep connection. Three participants were less reliant on the ‘safety net’ as they wished to use other avenues of support such as their family.

Furthermore, there was a desire in some participants to ‘move on’ from this period in their life meaning the connection to ICJ and consequently the constant reminder of cancer, was not required:

“I’m trying to get cancer out of my head and I’ve met people who don’t have families and they need the support. And if there was a time that I wanted to talk about cancer then that’s fine but not today. Today I live with it and get on with my life” (Interview 9, male]

DISCUSSION

Improving the Cancer Journey (ICJ) is the first cancer service of its kind in the UK. These interviews provided themes that highlighted how and why this form of support may make a positive impact on the lives of people affected by cancer. Namely, individuals valued the opportunity to discuss their concerns with someone outside of the clinical environment. Subsequently, these discussions enabled ICJ to provide personalised guidance and support based on individual need. This support came in many forms, including referral to other agencies for specialist needs, or more often by helping individuals to navigate state payment systems and obtain financial help they were entitled to. This was perceived positively as it reduced financial burden, created the confidence to self-manage and left participants feeling reassured that should they require any further support in the future they would know where to access it.

The views of participants in this study confirm previous research into the important components of coordinated cancer care. For example, Williams *et al* (2004) and Walsh, Young, Harrison, Butow, (2011) highlighted that having a ‘key contact’ when diagnosed with cancer is beneficial as they can alleviate feelings of anxiety and provide patients with greater confidence to deal with situations when they arise. Further, Walsh *et al* (2011) noted the importance of needs assessment in the successful delivery of coordinated care.

Wider research on holistic needs assessment has predominantly focused on assessments facilitated by clinicians, usually in outpatient clinics (Richardson *et al.*, 2007; Snowden *et al.*,

2012). This literature largely concentrates on identifying concerns specific to particular pathological groupings, such as people with bowel cancer (Taylor, Cummings, & McGilly, 2012); or the feasibility of conducting assessments of need in gynecological cancer (Sandsund *et al.*, 2017). This research helps clinicians to understand the range and prevalence of particular concerns. However, there is a lack of research on whether the identification of wider concerns leads to any improvements in patient outcomes. Further, there is little consideration as to what impact, if any, the environment and/or the profession of the assessor may have on the type of concerns raised. In short, evidence on the process and the value of HNA *to patients* is limited. This study begins to address this gap.

It is known that individuals value the opportunity to discuss their holistic needs (Snowden *et al.*, 2011, Biddle *et al* 2016). However, some patients do not perceive ‘non-clinical issues’ to be within the remit of healthcare professionals, leading to the underreporting of non-health related problems (Biddle *et al* 2016). Our findings indicated that inviting a non-health professional to explore holistic needs appears to have mitigated this issue. Link officers provided a ‘route to unexpected support’. Participants prioritised and raised practical and financial concerns because they perceived that these concerns could be met by the link officers ‘non-clinical ‘expertise.

Therefore, it seems reasonable to conclude that people perhaps prioritise the needs they want to discuss based on their understanding of the expertise of the person conducting the assessment. If this is true and generalizable, the best way of meeting as many needs as possible is to provide people with a diverse range of clinical, practical, financial, social, psychological and spiritual support, so that people feel they can easily discuss their concerns to the person trying to support them. This is very much in line with the drive towards

creative, multi-agency joint working, as prescribed by current health policy (Department Health & Social Care, 2015; Scottish Government, 2016).

Yet not everybody viewed the service so positively. Therefore, it is important to recognise alternative explanations. A small minority struggled to remember their interaction with the link officer and one individual seemed disappointed that the support offered was not as they had anticipated. Further, it appears that those with pre-existing ‘safety nets’ (e.g. families and friends, financial and personal resources) or high levels of personal resources such as competence on the internet did not require this form of support. Nevertheless, these people contacted ICJ for some sort of help and did not find it there. This needs to be reflected on further but it is recognised that some people will not find benefit from or want the service. However, it remains the case that the service was beneficial for the majority of participants. In particular, it provided the greatest benefit to those who were less likely to manage their own health and therefore may have struggled to seek out the support themselves.

This study has implications for practice. It is increasingly understood that for care and support to be integrated it must be person-centred, coordinated and tailored to the needs of the individual (WHO, 2016; The Scottish Government, 2016; Department of Health, 2011). Accordingly, this paper has drawn attention to a service successfully operationalising this ideal. This is significant because developing successfully integrated care is complex. For example, different sectors and institutions often have separate IT infrastructure and funding models that prevent collaboration (Cortis, Ward, McKinnon, & Koczwara, 2017). Research that provides insight into initiatives that have successfully embedded integrated care can be used as a foundation of knowledge to inform and motivate colleagues across the cancer care profession. To that end, this local initiative has broader reach. For example, it addresses some

of the issues that have historically hampered previous attempts at distress management such as a perceived lack of time and training (Mitchell *et al* 2012). ICJ link officers receive ongoing training to provide them with local context and resource information. Further, as raised, patients do not always feel it is appropriate to talk to clinicians about non-clinical issues. Therefore, the best solution is a multidisciplinary team, matched to the holistic needs of the population they are set up to support.

Limitations

We acknowledge the following limitations: while the aim was to recruit a broad sample to explore the experience of using this service from an array of perspectives, the sample was skewed to more females and predominately one age band. Also, there was little ethnic diversity, although the sample was consistent with the local population in this regard. Those who responded were mainly enthused about the service meaning there were few negative elements discussed. The individuals who did not volunteer to be interviewed may have held negative views of the service. While we do not know if this was the case, we recognise this is a gap in our knowledge. In some instances, the participants struggled to recall their experience of the service. This could be a limitation of the wide sampling frame, including participants having last used the service up to one year prior to this research. Future research will limit involvement with the service to a narrower time frame and actively seek the views of those people who were invited to use the service but declined.

Finally, it is acknowledged that a related limitation of this paper is its possible generalisability to other geographical areas. ICJ is situated in a city with its own unique infrastructure and socioeconomic conditions (Dodds, 2014). For instance, there are considerable areas of deprivation within the city. Regardless of socioeconomic status most people experience financial issues following a cancer diagnosis. However, for those who are

already experiencing multiple disruptions in their life cancer can cause a considerable burden. As evidenced, ICJ had a positive impact on financial concerns which while clearly beneficial for these individuals the experience of such a service may not be the same in other areas. As this model of support is implemented across the UK further work should seek to understand the experiences of using this approach for different cultures and communities. This paper provides a starting point in ensuring that the patient perspective is part of this understanding.

CONCLUSION

Worldwide, very little research has focused on practical examples of services designed to meet non-clinical needs and concerns from the patient perspective. This study focused on understanding the experiences of people diagnosed with cancer who had received care from ‘Improving the Cancer Journey’(ICJ), a proactive holistic support service run by a joint health and social care board, operationalised by non-health ‘link officers’. Participants described the benefit of having one accessible expert to guide them through the complexity of their personal ‘journey’ and all the interrelated support services. The service acted as a ‘safety net’, with participants stressing the importance of knowing that ICJ was always there to help if needed. An important and related finding was that this safety net acted to improve self-confidence rather than create dependence. Participants took control of their own issues whenever they could. ICJ is a successful and hopefully transferable model of health and social care integration working efficiently to support those most in need. Longitudinal follow up is planned to explore the generalisability of these findings and their impact over time.

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