Seeking, Accepting and Declining Help for Emotional Distress in Cancer: A Systematic Review and Thematic Synthesis of Qualitative Evidence

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ABSTRACT

Many individuals affected by cancer who experience emotional distress report not wanting help. This review aims to understand why individuals affected by cancer seek, accept or decline help for emotional distress and what influences these actions. A systematic review and thematic synthesis of the qualitative literature was conducted. Using pre-defined search terms, four electronic databases were searched from January 2000-May 2016. Pre-determined inclusion and exclusion criteria were then applied. Identified papers were quality appraised. In total, 32 papers were included in the synthesis. Four themes emerged from data synthesis: attaining normality - the normality paradox; being emotionally literate; perceptions of help; needs-support gap. Attaining normality is ideographic, context dependent and temporally situated; some individuals maintain normality by not seeking/declining help whereas others seek/accept help to achieve a new normality. Thus, attaining normality paradoxically functions to explain both why individuals sought/accepted help or did not seek/declined help. Data indicates that a context dependent, systems thinking approach is merited to enhance psychosocial care. In particular, clinicians must actively explore the personal context of an individual's distress to ensure that help desired and help offered are mutually understood. Further research must address the limitations of the current evidence base to advance theoretical understanding.

Introduction

Many patients with cancer who screen positive for distress do not receive psychosocial care (Mitchell, 2013). In addition to professional and organisational barriers, it is recognised that many patients do not want formal help with their distress (Dilworth, Higgins, Parker, Kelly & Turner, 2014). Van Scheppingen et al. (2011) argue that there has been limited consideration of the construct of desire for help and help-seeking in psycho-oncology. However, insight into the phenomenon may be gleaned from studies examining psychosocial service uptake, desire for help-seeking or future behavioural intentions.

Variable rates of access to psychosocial services by patients are reported, ranging from 6-28 % in heterogeneous samples (Carlson et al., 2004; Ernstman et al., 2009; Kadan-Lottick, Vanderwerker, Block, Zhang & Prigerson, 2005; McDowell, Occhipinti, Ferguson & Chambers, 2011; Steginga et al., 2008) and from 28-50% in distressed samples (Azuero, Allen, Kvale, Azuero & Parmelee, 2014; Mosher et al., 2010; Mosher et al., 2014, Shimizu et al., 2005). Varying rates of desire for help have been reported in different cohorts (Baker-Glenn, Park, Granger, Symonds & Mitchell, 2010; Clover, Kelly, Rogers, Britton & Carter 2013; Clover, Mitchell, Britton & Carter 2015) ranging from less than two in ten (Tuinman, Gazendam-Donofrio & Hoekstra-Weebers, 2008) to two out of three (Tuinman, Van Nuenen, Hagedoorn & Hoekstra-Weebers, 2015).

Several variables predict desire for help and eventual service use and include: elevated distress (Carlson et al., 2004; Steginga et al., 2008); younger age (Corboy, McLaren & McDonald 2011a; Ellis et al., 2009; Merckaert et al., 2010; Mosher et al., 2013a; Scholten, Weinländer, Krainer, Frischenschlager & Zielinski, 2001; Steginga et al., 2008; van Scheppingen et al., 2011); being female (McDowell et al., 2011; Steginga et al., 2008); less social support, self-esteem and spiritual well-being (Carlson et al., 2004); discussing concerns with care providers (Kadan-Lottick et al., 2005); disease stage (Scholten et al., 2001); and ethnicity (Carlson et al., 2004; Kaddan-Lottick et al., 2005; Traegar et al., 2014). Understanding future behavioural intentions to service use confirms that more positive attitudes to help, predict eventual service use (McDowell et al., 2011; Steginga et al., 2008).

Informal caregivers of cancer patients experience significant rates of emotional distress and morbidity (Merckaert et al., 2013; Park et al., 2012; Vanderwerker et al., 2005) with caseness for distress reported between 10-30% and increasing to 30-50% in advanced

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cancer and palliative care populations (Pitceathly & Maguire, 2003). Meta-analyses have revealed a significant correlation between patient and informal caregiver distress (Hodges, Humphris & Macfarlane, 2005) and between patient and spousal caregiver distress (Hagedoorn, Sanderman, Bolks, Tuinstra & Coyne 2008).

Despite recognised high levels of unmet emotional and psychological need (Lambert et al., 2012) three recent studies report that many caregivers do not want help with their distress (Merkaert et al., 2013; Mosher et al., 2013b; Kobayakawa et al., 2016). Mosher et al. report that only 26% of distressed lung cancer caregivers used supportive mental health care services with patient receipt of chemotherapy as the only predictor to service use. Merckaert et al. (2013) report that only 24% of distressed caregivers of a heterogeneous sample of cancer patients desired formal support, with variables predicting desire for help being age, caregiver's level of distress and education levels. Both authors indicate the paucity of literature informing our understanding of help-seeking by informal caregivers.

In his seminal work 'Pathways to the Doctor', Zola (1973) conceptualises help-seeking as the individual's transition from 'person to patient' and explores factors influencing help-seeking. However, within the context of psycho-oncology, individuals already are patients or are family members/caregivers who are known to formal healthcare services and consequently any offers of a referral to psychosocial services made through on-going clinical interaction must either be accepted or declined. Nonetheless, similar to any individual in the general population, cancer patients and their family member/caregivers may also autonomously seek help for their distress independent of intervention from their cancer clinician. Cognisant of these differences we have used the term 'help-actions' as a collective term to encompass the three constructs of seeking, accepting or declining help for emotional distress in cancer.

To improve psycho-social care in cancer, in addition to identifying demographic or illness variables associated with help-actions for distress we need to develop our understanding of why individuals want/do not want help with their distress and what influences these help-actions. Qualitative studies examining the experiences, views, attitudes, perceptions, beliefs about the help actions of seeking, accepting and declining help for distress have the potential to provide such understanding. A systematic review of qualitative evidence would synthesise this understanding (Ring, Ritchie, Mandava &

Jepson, 2011) with thematic synthesis deemed an appropriate approach to explore the appropriateness and acceptability of interventions (Barnett-Page & Thomas, 2009).

The interdependence of distress between patients and caregivers/family members is widely acknowledged (Carolan, Smith & Forbat, 2015; Regan et al., 2015a) and Northouse et al. (2012) amongst others proposes that emotional distress and reactions to this distress occur within the patient-caregiver dyad unit. Thus, we purposefully chose to examine the qualitative literature reporting patients and/or caregivers/family members, rather than patients alone. Thus, the aim of this review is to understand why individuals affected by cancer (i.e. patients and/or their caregivers/family members) seek, accept or decline help for distress and what influences these help-actions.

Methods

We conducted a systematic review and thematic synthesis of qualitative studies using methods proposed by Thomas and Harden (2008).

Search strategy; inclusion and exclusion criteria; screening process

Locating qualitative data is recognised as potentially problematic. Historically, qualitative studies were not indexed in databases while the focus of qualitative research may not be explicit in the title or abstract, moreover search strategies such as PICO are not considered optimal in searching qualitative evidence (Cooke, Smith & Booth, 2012; Ring et al., 2011). To maximise retrieval of studies for inclusion we adapted the SPIDER tool which is a structured search strategy tool developed for qualitative and mixed method research comprising five domains: Sample, Phenomenon of Interest, Design, Evaluation, and Research type. (Cooke et al., 2012). First, we developed search terms pertinent to the first two domains of SPIDER, 'sample' and 'phenomena of interest'. Next, we developed inclusion and exclusion criteria relating to all domains of SPIDER (Box 1) to ensure that all included papers were adequate and relevant for data synthesis (Letwin et al., 2015). Studies providing insight into the phenomena of help-actions for distress i.e. seeking, accepting and declining help were included. Orientation to obtaining help is included within Rickwood, Thomas and Bradford's (2012) conceptual definition of help-seeking in adult mental health care. Thus, papers which included insight into orientation to obtaining help (desire for help) were included. Congruent with our stated research aim, only studies reporting primary data from

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qualitative studies or a qualitative component of a mixed-method study were included in the synthesis and therefore quantitative studies and reviews were excluded. Search terms used and the search strategy employed are detailed in appendix 1.

INSERT BOX 1 HERE

Box 1: Inclusion and Exclusion criteria

	Inclusion	**Exclusion**
1.**S**ample	Includes adult cancer patients and/*or* adult caregivers/family members of adult cancer patients. Cancer diagnosis (any stage or type). Palliative care populations if > 90% of sample had cancer diagnoses.	Bereaved adult caregivers/family members. Proxy respondent only samples. Healthcare professionals (HCP) only samples.
2.**P**henomena of **I**nterest	The focus of the paper or significant findings* from the paper inform insight about help-actions[†] as to why individuals seek, accept or decline help for emotional distress in cancer and/or what influences this.	Papers where findings about help-actions[†] do not provide significant insight as to why individuals seek, accept or decline help for emotional distress in cancer and/or what influences this.
3.**D**esign	Original research study; peer reviewed publication. Cross-sectional or longitudinal study design.	Reviews, editorials.
4.**E**valuation	Insight into views, experiences, attitudes, perceptions, beliefs, feelings, knowledge or understanding of help-actions	
5.**R**esearch type	Any qualitative study Qualitative component of mixed-method study	Quantitative study Quantitative component of mixed-method study
6.Language	English only	Non-English

For example either a theme, subtheme or concept within the paper
[†]This can encompass any element of the process of orientation to obtaining help (desire for help), future behavioural intention or observable behaviour.

Electronic databases (MEDLINE, CINAHL, PsycINFO and Behavioural Sciences Collections) were searched with a date restriction imposed to include publications from January 2000 onwards. These dates ensured that while comprehensive in its scope, the review remained contemporaneous to inform current clinical practice, reflecting publication of the first clinical practice guidelines in 1999 (Holland, 1999). The search was limited to English only publications as there was no facility to translate articles of another language. The search was initially conducted in August 2015 and updated in May 2016. The search strategy identified 6,189 articles after removing duplicates 5,108 titles and abstracts were screened using inclusion and exclusion criteria which identified 98 possible papers. Screening of papers was independently conducted by CC and GD with discrepancies agreed by consensus. The identified 98 full-text papers were reviewed by CC, and another team member (AS, LF or GD) with any discrepancies agreed by consensus. A total of 32 full text papers were included in the review (Fig.1).

Quality assessment

Considerable debate exists as to how methodological quality in qualitative studies is judged and strict adherence to reporting guidelines may result in insightful papers with minor methodological flaws being excluded from the synthesis (Campbell et al., 2011). All thirty two papers were critically appraised by CC using the CASP Qualitative checklist (Critical Appraisal Skills Programme n.d). This is a systematic, structured, quality appraisal tool which address ten criteria via the use of core questions (Table 1). Study quality was ascribed as follows: high quality studies met eight to ten criteria; medium quality studies met between five to seven criteria; and low quality met less than five criteria (Kanavaki et al., 2016). The tool was not used for exclusion purposes but to enhance understanding and to identify methodological limitations of primary studies and papers (Campbell et al., 2011).

INSERT FIG. 1 HERE.

Data extraction

The following data was extracted and tabulated from the primary studies: authors, context, aims, sample, design, data collection and method of analysis, quality appraisal, and study limitations. All the text from the results/findings sections from both the abstract and the full-

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text papers were imported verbatim into QSR NVivo (Version 10) software for qualitative data analysis.

Synthesis

Findings from the primary studies were synthesised using the three stage method of thematic synthesis described by Thomas and Harden (2008). First, free line by line inductive coding of the data from the primary studies i.e. results or findings sections of both the abstract and the full-text papers. During this stage only data derived from patient and/or caregiver perspectives from the primary data was coded i.e. data from the proxy respondents or healthcare professionals was not coded. Next, free codes were compared and contrasted with related codes grouped together as descriptive themes. In the final stage, analytical themes were derived by interpreting the relationships and meanings within and between these descriptive themes. Thus, thematic synthesis seeks to 'go beyond' the primary studies to generate new interpretive constructs, explanations or hypotheses (Thomas et al., 2008). Data extraction and thematic synthesis was conducted by CC. Critical development and sufficiency of the analytical themes from the primary data was reviewed by AS and sufficiency of the overarching synthesis was reviewed by AS and LF.

Results

Study characteristics

The thirty two papers, reporting thirty studies, were published between 2004 and 2016 and are listed in Table 1. The geographical context of the thirty two papers were as follows: UK (N=11), Australia (N=12), Canada (N=3), Germany (N=2), Netherlands (N=1), Sweden (N=1), New Zealand (N=1), and USA (N=1); five were rural settings (Corboy, McDonald & McLaren, 2011b; Fuchsia Howard et al., 2014; Gunn, Turnbull, McWha, Davies & Olver, 2013; Pascal, Johnson, Dickson-Swift & Kenny, 2015; Pascal, Johnson, Dickson-Swift, Dangerfield & McGrath, 2016). The majority of studies were cross-sectional with only two longitudinal study designs (Olson, 2014; Shaw et al., 2013). Informing theory was used in five papers (Braamse et al., 2016; Corboy et al., 2011b; Mosher, Given & Ostroff, 2015; Olson, 2014; Pascal et al., 2016) and two papers used policy frameworks to inform data analysis (Harley, Pini, Bartlett & Velikova, 2012; Maguire, Forbat, Kearney & Rowa-Dewar, 2009). The majority of papers were patient-only samples, four reported caregiver-only

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samples (Mosher et al., 2015; Olson, 2014; Shaw et al., 2013; Sinfield, Baker, Ali & Richardson, 2012) and eight were multi-perspective (Corboy et al., 2011b; Docherty, 2004; Ekberg et al. 2014; Högberg, Sandman, Nyström, Broström & Stockelberg, 2013; Maguire et al., 2009; Neumann et al., 2010; Regan, Levesque, Lambert & Kelly, 2015; Tan, Butow, Boyle, Saw & O'Reilly, 2014). Only four papers reported from distressed or predominately distressed populations (Lambert et al., 2014; Mosher et al., 2015; Reeve, Lloyd-Williams, Payne & Dowrick, 2009; Steele & Fitch 2008) with caseness for distress reported using standardised self-report measures, study questionnaires and clinical interview (Table 1).

Cancer type was subdivided as follows: single cancer site cohorts (N=9; 3 lung, 3 melanoma, 2 prostate, 1 breast), system specific cohorts (N=8; 4 haematological, 2 gynaecological, 1 urological, 1 upper GI cancers), and mixed cancer type cohorts (N=15). Cancer stage was described as follows: not reported (N=17), early (N=1), mixed stage (N=10) and advanced/palliative care (N=4). Time from diagnosis was described in twenty papers; in ten papers this was prospectively described within the inclusion criteria and in ten papers this was reported retrospectively within the study findings. Table 1 presents the authors, context, aims, sample, design, data collection and method of analysis, quality appraisal, and study limitations.

INSERT TABLE 1 HERE

Data synthesis

Four themes were emergent from data synthesis which we termed: attaining normality - the normality paradox; being emotionally literate; perceptions of help; and needs-support gap. Table 2 illustrates papers contributing to the development of the four themes specifying the populations from which samples were derived; indicating that all four themes were evident in differing populations of patient, caregiver, multiperspective and distressed populations.

INSERT TABLE 2 HERE

Attaining normality - the normality paradox

The theme 'attaining normality' emerged from data synthesis to explain an individual's help-actions for distress. Help-actions appear interwoven with the individual's desire to either to

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maintain their concept of normality or to seek a new normal, when normality is disrupted by illness experience. Perceptions of normality appear influenced by three interrelated concepts: meaning of distress within cancer experience; perception of self after cancer; and the meaning ascribed to seeking, accepting or declining help. Thus, perceptions of normality appear to be ideographic and unique to each individual. Some individuals sought to maintain normality by not seeking/accepting help whereas others sought help to normalise experience and create a new normal after cancer. Thus, 'attaining normality' paradoxically appears to function to explain *both* why individuals sought/accepted or did not seek/declined help.

Maintaining normality

Individuals did not seek/accept help for their distress as they did not want *"to focus on the disease and treatment"* (McGrath 2014, p.19), instead they sought to maintain the familiar and *"continuity of their everyday life"* (Reeve et al., 2009, p.357). Distress was often understood as an expected symptom within the normative experience of cancer. Judgements about the meaning of distress were informed by existing knowledge and social comparisons. Downward social comparisons were used to reframe illness experience leading individuals to accommodate their symptoms of distress with participants assessing that *"their situation was 'not bad enough'"* (Lambert et al., 2014, p.902) or they were not *"ill enough"* (Skea, MacLennan, Entwistle & N'Dow, 2011, p.122) to warrant help outside with their normal social networks:

> *"I always cope because someone's always in a worse situation than me and I read in the papers that they're dying from it and whatever, and I'm still alive".* (Tan et al., 2014, p.257)

For some individual's distress was viewed as an accepted normative coping response not requiring healthcare intervention, and was described as an integral aspect of the individual's *"core-self"* (Reeve et al., 2009, p. 363):

> *"I accept [the way I feel] and I try to find an answer for myself. And deal with... I ask myself questions and if the answer is not what I'm looking for then it just brings on a little bit of depression doesn't it? ... It's not depression. It's a quiet mode of deep thinking".* (Reeve et al., 2009, p. 363)

An individual's perception of self and the meaning individuals ascribed to seeking or receiving help appeared critical. Some individuals described not seeking help as a means to preserve their *"familiar self"* (Wenger & Oliffe, 2014, p.114) which appeared coterminous with perceptions of 'self' before cancer. This identity was conveyed by a strong desire for autonomy, the need to exercise control and a desire for self-reliance including emotional self-care:

> *"I try and manage everything myself. Because it's empowering, you know, cancer takes an awful lot of power away from you, you can't control that".* (Harley et al., 2012, p.253)

Seeking help was perceived as a sign of failure or weakness and incongruent with perceptions health and well-being:

> *"I think people are frightened to have counselling because they think it's a failure-even if they need it".* (Gunn et al., 2013, p. 2550)

Stoicism and the desire not to 'indulge' in emotional help-seeking were further amplified by the desire to maintain normative sociocultural role expectations informing identity. For patients, this included the desire to fulfil the role of the 'good patient' by not troubling staff with emotional concerns. Likewise, normative perceptions of the 'good caregiver' existed with the perception of emotional fragility being incongruent with the caregiver role. Prioritisation of patient need over caregiver need was described with thoughts of seeking help eliciting feelings of guilt:

> *"I wouldn't have ever gone to a professional because I wouldn't want to have time away from [my mother] or the kids . . . it would feel too indulgent".* (Mosher et al., 2015, p.56)

Gendered sociocultural perceptions of men's accounts of being strong and reticent to seek help were also evident:

> *"I think there is probably a general rule that men just say oh I will get on with it".* (Stapleton & Pattinson 2015, p. 1074)

Moreover, the influence of family scripts and cultural influences informing help-seeking were also voiced:

> *"In Europe you were raised to keep your opinions, your woes, your pain, your suffering… to yourself. No one else is interested".* (Mosher et al., 2015, p.56)

For some, the fear of stigma associated with seeking help for distress posed a potential risk to their perceived normality. This was described by some participants who *"associated therapy with disease and were afraid of being labelled as mentally ill"* (Neumann et al., 2010, p.812). Moreover, perceived stigma related to help-seeking were also expressed, particularly in rural areas, as was stigma related to cancer itself.

Seeking a new normality

Some participants described seeking help or accepting help for distress when distress transitioned from a symptom to a problem; this occurred if *"the symptom interfered with reaching a desirable goal"* (Braamse et al., 2016, p.4). This transition from symptom to a problem disrupted current normative or anticipated future function and was accompanied by a perceived loss of control. The presence (or not) of family informing transitions from 'symptom to problem' were apparent and some participants voiced how family had recognised this transition and sanctioned engagement with services:

> *"For patients who had received professional mental health care, patients' close relatives had played an important role in recognising the problem, convincing patients to seek help, selecting a suitable psychologist or contacting the general practitioner".* (Braamse et al., 2016, p.6)

Participants who sought or accepted help described doing so as a means to normalise emotions and to seek *"others' 'wisdom' to navigate the path ahead or re-envision their future"* (Wenger et al., 2014, p.117) to create a *"new normal"* after cancer (Beaver, Williamson & Briggs, 2016, p.83). Seeking help enabled some participants to share and benchmark their distress and coping strategies through a variety of formal support services; for some this led to a sense of empowerment, improved outlook and a perception of wellness:

> *"While the types of services varied, they were generally perceived as helpful for reducing uncertainty, fear and loneliness, normalising patients' experiences and in*

some cases encouraging a more positive outlook on their illness". (Gunn et al., 2013, p. 2549)

Negotiating a new normal was experienced temporally across the trajectory of cancer experience. Help appeared to be desired most at transitions points between different phases of cancer experience: diagnosis and initial treatment; after treatment; disease progression and life limiting prognosis; and into survivorship. Furthermore, retrospective consideration of whether help should have been sought was also conveyed. Some participants described the desire not to engage with services to enable individuals to move on from cancer and ill-health. However it was unclear whether the description of moving on referred to moving on to a new normal or a normal which was coterminous with normality before cancer.

Being emotionally literate

The theme of being emotionally literate depicts the extent to which participants were able to evaluate and express their emotional distress. This was conveyed through the two subthemes of emotional space and emotional disclosure.

Emotional space

Having insufficient emotional space to evaluate emotions was described by participants. This reduced emotional space limited an individual's opportunity to evaluate their distress and to consider any need for help. Reduced emotional space resulted from limited time, the burden of physical symptoms (including treatment related symptoms) and competing family issues. In addition, overwhelming emotional distress itself could also act to limit emotional space available and with this participant's ability to evaluate the need for any help:

"I needed someone who actually saw and grasped my concerns. I did not have the strength enough to do it myself". (Högberg et al., 2013, p.599)

Moreover, some individuals described consciously making an active choice to restrict their emotional space through distancing and distracting strategies. Engagement with emotions was perceived as indulgent, potentially disruptive to day to day life, and could also pose a risk of making one's situation worse:

"I didn't really go work through emotional things. . . . It is partly that, I am a little bit scared what you will find. And then if it doesn't work out, the way I saw my job was to look after [my husband] and 3 girls [and] two older parents. If you delve into the emotional and it doesn't resolve in a way, then you are in a mess, then what is going to happen. So . . . keep that gate closed (laughs)". (Olson 2014, p.243)

Emotional disclosure

While it was evident that disclosure of distress was not always synonymous with seeking or accepting formal help, failure to disclose distress could inhibit help-seeking and obtaining support:

"...of course I was putting a brave face on it for [my husband] all the time. Because you do, and I didn't get that support". (Maguire et al., 2009, p.1273)

Protective buffering, relational functioning and personal attributes emerged as important factors influencing distress disclosure and its perceived adverse impact on family relationships was also voiced. Non-disclosure of emotions was frequently described and was used to protect both the individual disclosing distress and the recipient of emotional disclosure:

"You don't want to share your hurt and your suffering with the family… I didn't want to upset them, I didn't want them to be worrying on my behalf. I like to put on a brave front but underneath I was really crumbling". (Tan et al., 2014, p.257)

For the individual disclosing distress, disclosure risked furthering distress, social discomfort, embarrassment, and invoked feelings of vulnerability. In contrast, some men described how non-disclosure of distress enabled them to maintain the protector role within familial relationships.

Whether recipients were perceived to have sufficient emotional capacity to cope with emotional disclosure influenced whether disclosure occurred; while primarily described with reference to family and friends this also applied to disclosure to healthcare professionals:

"When deciding whom to talk to participants chose the person that they felt could cope best with the burden of their problems". (Bird, Coleman & Danson, 2015 p.941)

Perceptions of reciprocal inhibition of disclosure by family and friends were also described, and achieved by unsupportive attitudes or closing down of emotional expression:

"... some men viewed those close to them as not being open to discussing emotions, describing how messages from friends and family to 'come back strong' or be 'all right' after the treatments left them feeling that these others did not anticipate or want to hear about their enduring emotional pain". (Wenger et al., 2014, p.118)

Discussion of cancer and emotions was considered as private within family and informal social networks and a reluctance to discuss feelings with healthcare professionals and 'strangers' was described:

"They [mental health professionals] don't really care. They're not a friend . . . they're detached; they're looking at us as a number . . . it's not like I'm talking to a friend or a family member that has feelings for us". (Mosher et al., 2015, p.55)

However, the emotional neutrality of a healthcare professionals or friends removed from family networks was also viewed positively and for some enabled anonymous disclosure of distress beyond their family networks:

"Sometimes you can discuss things better with someone who is distant and – you know – somebody being close isn't always a good thing, when you're discussing things with them because they can have their own emotions going on". (Ekberg et al., 2014, p.366)

The presence of trusting personal relationships, open communication and the assurance of confidentiality was perceived as important in facilitating disclosure of distress to healthcare professionals:

"...they [patients] would only discuss emotional matters with someone they had established a strong relationship with". (Clarke et al., 2006 p.70)

However, the desired qualities of compassion, empathy and communication skills were not wholly dependent on existing relationships but rather personal attributes of the healthcare professional. Some participants described that some healthcare professionals did not appear to recognise or address their emotional distress, as recounted by one participant *"the doctor*

didn't ask us 'Do you need any support?' I'd been crying, you know" (Sinfield et al., 2012, p. 531). Participants also described how healthcare professionals often prioritised physical symptoms:

> *"Many of the men interviewed noted that they [healthcare professionals] tended to discuss 'mainly procedural things I guess' (ID: P009), 'physical symptoms, treatments and what's going on with the disease' (ID: P004), rather than psychosocial concerns".* (Corboy et al., 2011b, p.178)

This led to uncertainty about what was permissible to express with some expressing a desire not to trouble professionals. Disclosure of emotional concerns to healthcare professionals was further inhibited by a perceived lack of available healthcare professional time by participants and by physical exhaustion. Distress screening featured in only one study where it was cited by patients as useful in alerting staff to distress, even if help was subsequently not sought (Lambert et al., 2014).

Perceptions of help

The perceived benefits and risks of disclosing distress are readily apparent in the preceding theme of emotional literacy. Differing perceptions of help existed and influenced whether individuals would seek help or engage with supportive care and included the following: (i) limited help available (ii) limited benefits of help (iii) risks of help (iv) benefits of help.

Limited help available

Some individuals described that help was limited with barriers to obtaining help identified. In some instances signposting or referral to supportive care services had not been offered or was unclear. Some described determining help available was *"left to what you can find out"* (Olson, 2014 p.245). Challenges and uncertainty in navigating healthcare systems existed with participants expressing uncertainty about knowing who to seek help from and language barriers were also identified. Moreover, some participants indicated not knowing what to expect after completion of treatment and not knowing whether help was available. This seemed to be heightened for those in rural areas who were remote from urban cancer centres:

> *"My local hospital, as far as that goes, nil support. But I didn't really expect, I didn't know what to expect so I just took it for granted as normal".* (Pascal et al., 2014, p.43)

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Access to supportive care services was generally perceived as problematic particularly in rural areas, although this was not uniformly described. Access to help was primarily influenced by the availability of services and logistical issues. Availability of face to face services was restricted by limited or inconvenient scheduling and lack of time to attend. While the availability of cancer nurse specialists was valued, variability in access was described. Logistical issues in attending face to face help were described with expense, distance and travel cited as barriers, although family members sought to address this by providing physical assistance and transport to access services. Alternative means of providing help such as telephone support help-lines and interactive web based support were considered useful in overcoming these issues.

Limited benefits of help

Some considered supportive care services to offer limited benefit. Services were described as having nothing additional to offer, mismatch in perception of need existed and individual situations were thought to be too complex to be helped:

> *"The attitude that I've got, I don't feel that they could sort of tell me anything I don't already know or don't already have… so I really don't need [psychosocial support]".* (Regan et al., 2015b, p.12)

However, it was apparent that knowledge and understanding of what psychosocial supportive care meant and what help was available was often limited or erroneous. Factors which contributed to this included: poor quality of information, language barriers, difficulty in processing information due to fatigue and physical ill health including treatment side effects:

> *"...most patients were aware that organisations, such as Macmillan [Supportive cancer care services] were available to cancer patients but many believed these services were for end-of-life care or 'if things got desperate'".* (Harley et al., 2012, p.252)

Risks of help

As highlighted in the maintaining normality theme, some participants believed that seeking/accepting help could undermine autonomy and perceptions of stigma existed. Moreover, perceived risks of help could deter engagement with services:

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"And there's nothing worse than, you talk with someone and you find out they can't be helpful and they brush you aside or something. I don't really need that. So, well, I don't put myself in that situation basically". (Brown et al., 2015, p.1537)

Some participants described accessing help as embarrassing or awkward while telephone support lines and peer groups were perceived as scary or intimidating. Some described the risk that engaging with support could risk worsening one's situation. Help through shared experience from peer support could further depress and risked future losses through deaths in new friendships. Some individuals were uncertain whether they could shoulder another's burden or worried that they would make others worse. The need for help to be safe and qualified was important to mitigate against potential risks. Concerns about addictive risks of medication were expressed by participants in only one study (Mosher et al., 2015).

Benefits of help

Normalising and bench marking experience was cited as a perceived benefit of help. Some individuals valued experiential knowledge over professional knowledge, and vice versa. Shared experience through peer support groups was described as particularly valuable for those seeking help to normalise experience. Peer support groups provided the opportunity for social comparisons and were valued as a source of information sharing and experiential knowledge, including development of coping strategies. As one participant expressed help was sought to:

"...see how they [other patients] were coping...listen to what they had to say. And, what suits them isn't obviously or necessarily gonna be good for me. But I can take bits and pieces from that and make it fit what I want". (Brown et al., 2015, p.1537)

Empathic solidarity received through peer support and from healthcare professionals was voiced as particularly important:

"... if you can relate to somebody who's been through the same type of problems as you are enduring it's really comforting". (Docherty, 2004, p.91)

Perceptions about the specific benefits of different types of help available, influencing desire for help was evident and the perception that help offered should be specific and tailored to age, rural geographical context, cancer type, social circumstances and roles was described.

Furthermore, it was perceived that psychosocial assessment and supportive care should extend beyond the patient to include the family. Finally, some carers voiced the benefit of seeking help as means to have 'time out' from caregiving roles.

Needs–support gap

Engagement with supportive care service appeared to be influenced by whether emotional needs and preferences for meeting those needs could be met by existing informal networks (whereby formal help was not sought or declined) or whether a shortfall or gap existed (whereby formal help was sought or accepted). Emotional needs were frequently met within existing normative family and lay social networks. Receipt of such support from informal social networks was often preferred, positively viewed and cited as sufficient for individuals' needs. As described by one participant*, "family is key and all you need"*(Lambert et al., 2014, p.903). It was acknowledged that help from social networks could include incidental professional help from friends and family members who were also healthcare professionals.

In contrast some individuals described limited support from informal and lay networks to meet their emotional need and thereby promoting engagement with formal help. A variety of factors reduced available informal and lay support and included: reduced social networks, geographical isolation, reduced coping capacity within their own family and social network, unsupportive family attitudes and relational conflict:

> *"...he didn't really want to talk about it, but for me I need to talk about it [. . .] I very much wanted to sit face-to-face with somebody and for them to give me the time to help me".* (Sinfield et al., 2012, p.530)

The depiction of an overwhelming deficit in the needs-support gap sanctioning engagement with services was described by some individuals. This tipping point was sometimes clearly demarcated and conveyed by the use of emotive terms such as *"desperate"* (Harley et al., 2012; Steele et al., 2008),*"overwhelmed"*(Lambert et al., 2014),*"crisis"* (Beaver et al., 2016),*"breaking point"* (Lambert et al., 2014),*"catastrophic"* and *"last resort"* (Mosher et al., 2015). This overwhelming deficit appeared influenced by a number of factors including symptom severity, multiple concurrent stressors, successive losses and exhaustion of coping strategies. In addition to distress severity, the chronicity of distress was important with help sought when distress was viewed as persistent. In contrast if distress was perceived as

transient or attributable to a finite concurrent stressor then help was less likely to be sought. However, such overwhelming deficits were not uniformly described.

Discussion

An individual's desire to attain normality appears critical to understanding why individuals seek, accept or decline help. Attaining normality is ideographic, context dependent, temporally situated and paradoxically functions to explain both why individuals sought/accepted help to achieve a new normality or did not seek/declined help to maintain normality. These findings align with a recently published qualitative study where conceptions of continuity and discontinuity of normality were emergent within patients' experience of cancer (Baker et al., 2016). Baker et al. (2016) highlight that these contradictions are consistent with findings which suggest that biographical flow and biographical disruption can paradoxically co-exist within an individual's cancer experience (Hubbard & Forbat, 2012). These apparent inherent contradictions would lend support to our assertion that help-actions can paradoxically support both attainment of continuous and discontinuous (new) normalities within cancer experience.

This synthesis suggests that individuals use knowledge informed by normative-sociocultural perceptions and reinforced by direct social comparisons with others, to evaluate whether their distress is normative. This echoes Baker et al.'s (2013) findings that patients do not always perceive distress as a symptom which warrants professional intervention. Action, in terms of seeking or accepting help for distress occurs when the experience of distress becomes problematic and disrupts the equilibrium of normative experience. Thus, distress shifts from a symptom which can be accommodated to a problem requiring external help to restore one's equilibrium of normal. Similar findings are described in generic adult mental healthcare whereby individuals accommodate distress and engage in a *"cycle of avoidance"* in help-seeking from formal care (Biddle, Donovan, Sharp & Gunnell, 2007 p.983). Repeated efforts to accommodate distress cause perceptions of normality to shift and stretch over time, until a threshold of distress is eventually reached, often at a point of crisis, at which point help is finally sought (Biddle et al., 2007).

Findings from data synthesis may be understood within the context of Dingwall's illness action model (2001). Dingwall's model has its historic origins in the sociology of deviance, but applied to health where people want to be perceived as ordinary and illness is perceived

as a failure. In this model individuals use a 'common stock of knowledge' to evaluate how much symptoms deviate from socio-culturally derived perceptions of normal, this evaluation informs the decision to act, which is subsequently monitored in an iterative process. Help is sought as a means to restore the equilibrium of normal. The evaluation of symptoms may also involve others; this is salient to our findings where recognition of distress as problematic and subsequent decision making to seek help was influenced by family and informal social networks. However, the iterative nature of Dingwall's model means that the equilibrium of normal and what is *"accepted as 'normal' may be different to the 'normality' of the past"* (Wyke, Adamson, Dixon and Hunt, 2013 p.81). Finding from our synthesis describing retrospective consideration of whether distress should have been sought and descriptions of seeking/accepting help to attain a new normality, suggests that perceptions of normality are not fixed but malleable over time.

The reluctance to disclose emotions to informal and formal networks because of perceived social constraints is widely acknowledged within the cancer literature (Adams, Winger & Mosher, 2015; Lepore & Revenson, 2007). Our review additionally supports the idea that social constraints, including stigma operate to inform help-actions for distress. Our findings are consistent with a recent systematic review from mainstream adult mental health care, which reveals social constraints and stigma related to disclosure of concerns as the commonest barrier to help-seeking for mental health problems (Clement et al., 2015).

Our findings indicate that normative socio-cultural perceptions and social constraints appear critical in informing evaluations and judgements about the normality of distress and help-actions for distress. Public health initiatives employing participatory societal discourse to shift such sociocultural perceptions (Salmon, Clark, McGrath & Fisher, 2015) may have utility enhancing psychosocial care uptake. Such initiatives must also challenge perceived social constraints to improve emotional literacy and acknowledge the role of stigma; distinguishing stigma related to mental health, stigma related to help-seeking (Tucker et al., 2013) and to cancer itself. Given the rising prevalence of cancer (Bray, Ren, Masuyer, & Ferlay, 2013) and the existing high rates of mental health problems more generally (Kessler et al., 2009) development of policy aimed at the whole population and not simply those receiving cancer care would derive most benefit.

At the individual therapeutic level it is imperative that clinicians actively explore the individual's appraisal of their distress, their socio-cultural beliefs about mental health and

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help-seeking (including stoicism and stigma) and actively enquire about support available from informal social networks (Hansen & Aranda, 2012). This will ensure congruence between help offered by healthcare professionals and help desired by individuals. Doing so may also offer a therapeutic window to allow healthcare professionals to constructively challenge any misconceptions held, including perceptions about the type and availability of formal help available. Given that our review indicates that help-actions appear constructed within familial relationships and social networks, a relationship centred approach involving family members and significant members of the individual's social network should be considered.

Findings indicate that disclosure of distress to healthcare professionals is promoted by the presence of a pre-existing relationship and time. However, recent literature suggests that it is the quality of the relational interaction which promotes communication and supportive care (Stajduhar, Thorne, McGuinness & Kim-Sing, 2010) and not necessarily the presence of a pre-existing relationship (Hill, Paley & Forbat, 2014). Moreover, clinician expertise and attributes can produce the 'illusion of time' to promote open communication (Thorne, Hislop, Stajduhar & Oglov, 2009).

Perceptions about the availability of help and risks associated with seeking help echo Dilworth et al.'s (2014) synthesis which revealed lack of information about services (19%); logistical issues (17%); lack of confidence in services (13%); and negative perceptions of help including perceived stigma (10%) as a barriers to psychosocial care. Our findings of the perceived 'benefits of help' including empathic solidarity influencing help-seeking could proffer alternative insights to enhance service uptake. This is supported by a recent action research study which demonstrated high rates of acceptability of on-line web resources which were *"written by people who understand what I am going through"* (Fennell et al., 2016 p.10). This suggests that participatory research methods may enhance our understanding of help desired and promote engagement with services.

Three papers in this review used Andersen's (1995) behavioural model of access to healthcare as informing theory to frame their approach. Deterministic models such as Andersen's seek to identify characteristics to determine or predict uptake of help and services (Biddle et al., 2007). Adopting a similar deterministic approach, McGrath (2013) included in this review, proposes the concept of receptivity, defined as *"the range of factors (individual, social and geographical) that affect an individual's desire or ability to receive or engage with*

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supportive care services" (p. 36) which she dichotomously categorises as either low or high receptivity. We posit that the themes of being emotionally literate, perceptions of help and needs-support gap could be ascribed deterministically (e.g. high emotional literacy versus low emotional literacy) to reflect a spectrum of high and low receptivity to help and engagement with services at the health care interface. However, critics argue that deterministic approaches have a limited explanatory potential as they conceive help-seeking as a singular decision rather than a complex dynamic social process (Biddle et al., 2007; Wyke et al., 2013).

Dynamic theoretical models such as Dingwall's Model and the Common Sense Model of Illness (Leventhal, Meyer, & Nerenz, 1980) have both been used to understand help-seeking for cancer symptoms (Scott, Walter, Webster, Sutton & Emery, 2013). The Common Sense Model is informed by the self-regulation of health and illness in response to a perceived threat and has generally been generally applied in the context of responses to physical symptoms and illness particularly chronic illness (Hagger & Orbell, 2003; Leventhal, Phillips & Burns, 2016). Whereas, Dingwall's Model is informed by the sociology of deviance and the maintenance of normality, we believe the latter model aligns more closely with our findings.

Building on Dingwall's (2001) and McGrath's (2013) models we present the 'Attaining Normality Model' (Fig.2) to visualise our current understanding of help-actions for distress. We posit that ideographic interpretations of distress and subsequent enactment of help-actions for distress are influenced by the interaction of the four themes within the central box influences whether an individual seeks to maintain normality, associated with a low receptivity to help (non-seeking or declining help) or whether the individual seeks a new normality associated with a high receptivity to help (seeking or accepting help). Critically, these interactions occur within each individual's personal and sociocultural context of care. The temporal arrow indicates that this process occurs iteratively at multiple time points across an individual's cancer experience. Further research is needed to explore how interconnections between these four themes are operationalised during the dynamic and complex process of help-action decision making to progress understanding.

INSERT FIG.2 HERE

Strengths and limitations

This is the first systematic review and qualitative synthesis of help-actions for emotional distress. Given that the overwhelming majority of papers have been published since 2010 we believe this review provides timely and valuable insight into a rapidly evolving and important area of research. Studies were generally of a high quality, perhaps reflecting the advent of qualitative reporting guidelines (e.g. COREQ-32) (Tong, Sainsbury & Craig, 2007). Only English language papers were included and therefore data synthesis may have limited relevance to non-English speaking countries. We acknowledge that papers informing synthesis were derived from westernised contexts of care which might influence normative sociocultural perceptions expressed in this synthesis. Only electronic data bases were searched and it is possible that some related studies may not have been identified. Despite these limitations we believe that our search strategy was sensitive, as evidenced by the significant number of included qualitative papers in contrast to earlier related reviews (Dilworth et al., 2014).

The quality appraisal process used in this review identified significant limitations of the current evidence (Letwin et al., 2015). A significant proportion of the studies were drawn from the UK which preferences publically funded healthcare and thus the findings may have less applicability in countries exclusively using market based healthcare insurance systems. The reporting of cancer stage was poor and time from cancer diagnosis was only prospectively considered in ten studies. The majority of studies were heterogeneous with regard to cancer type, cancer stage and time from diagnosis and greater consideration should be given to sampling approaches to facilitate exploration of distinctions specific to these varied subgroups. Only four studies sampled distressed populations which places limits on our understanding of how help-actions are operationalised within populations with differing rates of distress. Future research should address this issue, to inform debate as to whether help should be offered on the basis of stratified distress assessment or whether other measures may better predict engagement with help.

The type of help available or offered was often poorly qualified and quantified. Thus, insight into whether subjective perceptions of help available reflected objectively reality and how the type of help offered influenced help-actions was limited. Only two studies used a longitudinal design; future research should seek to employ longitudinal design to further illuminate the dynamic process of help-actions over time. The heterogeneity of the studies does place some limits on synthesis. Most studies included in the review adopted a thematic

approach to data analysis with a paucity of studies using a phenomenological approach or an inductive theory generating approach. Further research adopting such methodological approaches would enable a richer understanding of lived experience of the process of seeking and engaging with help, including how subjective perception and social constructions of normality influence this.

Conclusion

Taken together the findings suggest an individual's perception of their distress, their ability to evaluate and disclose their distress, and subsequent enactment of help-actions are context dependent and are constructed within their personal social networks and wider sociocultural contexts. Some individuals feel they do not need help because of existing supportive social networks, some perceive that help would not be helpful or even potentially harmful, and some do not engage with help to maintain their perception of normality; suggesting that in some instances, lay and professional perceptions of distress and need for help differ. Action to enhance psychosocial care must be cognisant of these potential differences and acknowledge the varied contextual elements informing help-actions.

We assert that a systems thinking approach (Peters, 2014) should be adopted to enhance engagement with psychosocial care. At the exo-level, participatory societal discourse should seek to challenge perceived social constraints to shift societal norms. At the macro-level, healthcare providers should critically examine current strategies to enhance distress disclosure and use public and patient involvement to promote co-production in service design and delivery. At the micro-level, clinicians should actively explore the individual's personal context of distress to ensure that help desired by individuals and help offered by healthcare professionals is mutually agreed. Doing so will foster the development of psychosocial care which is relevant, acceptable and accessible to those affected by cancer. Finally, further research must address the significant limitations of the current evidence base to advance theoretical understanding.

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Figure1. Study selection flow diagram


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┌─────────────────────────────────────┐          ┌─────────────────────────────────────┐
│ Records identified through database  │          │ Additional records identified through│
│              searching               │          │            other sources             │
│             (n=6,189)                │          │       (n=0) not undertaken           │
└─────────────────────────────────────┘          └─────────────────────────────────────┘

              ┌─────────────────────────────────────┐
              │    Records after duplicates removed  │
              │             (n=5,108)                │
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              ┌─────────────────────────────────────┐      ┌─────────────────────────┐
              │     Titles & abstracts screened      │─────▶│    Records excluded      │
              │             (n=5,108)                │      │       (n=5,010)          │
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              ┌─────────────────────────────────────┐      ┌──────────────────────────────────────┐
              │   Full-text articles assessed for    │      │      Full-text articles excluded     │
              │             eligibility              │─────▶│                (n=66)                │
              │               (n=98)                 │      │                                      │
              └─────────────────────────────────────┘      │ Not about help-actions for distress = 45 │
                                                            │ Generic help-seeking = 6             │
              ┌─────────────────────────────────────┐      │ Minimal/Descriptive accounts of help-│
              │    Full-text articles quality        │      │ actions for distress = 15            │
              │    appraised using CASP              │      └──────────────────────────────────────┘
              │               (n=32)                 │
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              ┌─────────────────────────────────────┐
              │    Full-text articles included       │
              │          In synthesis                │
              │               (n=32)                 │
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Table 1. Summary of the aims, sample, design, quality appraisal and limitations of the papers included in the review

Author Year Country	Context	Aim	Sample (Size, sex & age/ cancer type & stage/ psychosocial help accessed/ sampling approach described)	Design/Data collection/Data analysis	CASP criteria (n/10)	Limitations
Pascal et al. 2016 Australia	Rural community	What are the informal and formal psychosocial support needs of people with cancer living in regional/rural communities?	19 patients (6 male,13 female; age 40-82)	Qualitative, phenomenological (Heideggerian) Cross-sectional	9	Preponderance of females and breast cancer. Rural population.
			Mixed cancer type Mixed cancer stage Time since diagnosis: 0.5-6 years	Individual in-depth interviews		
			'Most' participants did not access or were not referred to help-not further qualified			
			Purposive and theoretical	Abductive approach Thematic analysis		
Beaver et al. 2016 UK	4 Hospitals	To explore the experiences of women receiving neo-adjuvant chemotherapy for breast cancer	20 patients (all female; age 30-67; mean age 48)	Qualitative, exploratory Cross-sectional	9	All female sample. Single cancer type. Predominately younger women.
			Breast cancer No cancer stage described Neo-adjuvant chemotherapy in last 12 months 45% of participants had received counselling	Individual semi-structured interviews (face to face)		
			-	Content analysis		
Braamse et al. 2016 Nether-lands	Six hospitals	To explore patients' needs and help-seeking behaviour is relation to their experienced	20 patients (7 male; 13 female; age 28-66; mean age 52.3)	Grounded theory approach	10	Predominately female population. A third party was present in 3 interviews which
			Haematological malignancy 18 remission; 2 progressive	Individual semi-structured interviews (face to face)		

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			symptoms and problems	disease 2 years since autologous stem cell transplant	In 3 interviews a third person was present.		may have impacted on data collection.
				'Some' participants accessed help-not further qualified			
				Purposive and theoretical	Constant comparative method		
Regan et al. 2015b Australia	Support groups, psycho-oncology services, and hospital-based oncological services	To explore the perspectives of Health Care Professionals (HCPs) and couples on the provision of couple focused psychosocial care in routine cancer services.		20 patient-partner dyads (Patients: 13 male 7 female; mean age 64.6. Partners:7 male, 13 female; mean age 63.5) 20 HCPs	Qualitative, exploratory, multi-perspective Cross-sectional	10	Low response rate in sampling approach. Predominance of prostate and breast cancer. No same-sex couples participated. HCPs known to researchers. Authors cite risk of selection bias
				Mixed cancer type No cancer stage Average time since diagnosis: 14.4 months	1:1semi-structured interviews with HCPs and 1:2 interviews with couple dyads Patient-partner dyads (face to face) & HCP (face to face & telephone)		
				Numbers of participants accessing help not described.			
				Convenience	Framework approach.		
Brown et al. 2015 Australia	Chest clinic Single hospital site	To explore the supportive care needs and preferences of lung cancer patients.		10 patients (8 male, 2 female; age 50-89)	Qualitative, exploratory (inductive grounded theory approach) Cross-sectional	8	Predominately male. Single cancer type. Predominately older patients (>70yrs). Authors state possible sampling bias to patients with better functional status. Authors cite uncertainty if data saturated.
				Lung cancer Current or past medical history of lung cancer *5 Follow up/survivor* *2 Under/investigation* *3 Palliative*	Individual semi-structured interviews (face to face)		
				No participants had accessed support groups or helplines			
				-	Constant comparative		

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Stapleton and Pattison 2015 UK	Clinical trials unit and a palliative care unit (tertiary cancer centre)	To understand how men experience their advanced cancer in relation to their perceptions of masculinity.	Eight patients (all male, age 26–68)	Qualitative, descriptive & exploratory phenomenological Cross-sectional	10	All white heterosexual men. Predominately married men. No recruitment occurred from palliative care unit.
			Mixed cancer type Advanced or metastatic cancer	In-depth open interviews (face to face)		
			Numbers of participants accessing help not described			
			Purposive	Colazzi's seven-stage framework		
Bird et al. 2015 UK	Specialist cancer centre	To explore the patients' experience of having malignant melanoma, their related support needs and the processes that lead to these needs being met.	11 patients (5 male, 6 female; age 31-83)	Qualitative, exploratory constructivist grounded theory approach Cross-sectional	10	Single cancer type.
			Malignant melanoma Cancer stage II-IV Time since diagnosis: 1-11 years	Individual interviews, initial interviews open, later interviews semi-structured. (face to face)		
			2 participants had accessed complementary therapies and counselling			
			Theoretical sampling	Constant comparative		
Stamataki et al. 2015 UK	Two tertiary cancer hospitals	To explore the supportive care needs of melanoma patients	15 patients (7 male, 8 female; age 27-78, mean 52)	Qualitative, exploratory Cross-sectional	10	Single cancer type. Sample derived from cross-sectional study which had identified participants as having highest level of needs.
			Malignant melanoma Cancer stage I-III Time since diagnosis: 3 months-5 years	Individual semi-structured interviews (face to face)		
			Numbers of participants accessing help not described			
			Purposive	Thematic analysis.		
Mosher et al. 2015 USA	Oncology clinic Cancer centre	To identify barriers to mental health service use among distressed family caregivers of lung	21 distressed[‡] caregivers not receiving mental health services (5 male, 16 female; age 30-71, mean 53) ‡ ≥8 on the Anxiety or	Qualitative, descriptive Cross-sectional	9	Single cancer type. Majority of participants were married women and middle to upper

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		cancer patients.	*Depression subscales of HADS*			class socioeconomic status. Only examined those not using mental health services.
			Non-small cell lung cancer Mixed cancer stage *I-II 29%* *III-IV 67%* *Missing 5%* All participants had not received mental health services	In depth semi-structured interviews (telephone) Standardised assessments of their health, well-being and mental health service utilisation (telephone)		
			Purposive	Theoretical thematic analysis		
Pascal et al. 2015 Australia	Rural community	To highlight gaps in formal psychosocial care for cancer survivors in rural communities.	19 patients (6 male, 13 female; age 40-82)	Qualitative, exploratory Cross-sectional	9	Preponderance of female and breast cancer. Rural population.
			Mixed cancer type Stage not described Cancer survivor Time from diagnosis: 6 months-6 years	Individual in depth-semi-structured interviews Tan		Preponderance of female and breast cancer. Rural population.
			'A few' participants had accessed help-not further qualified			
			Purposive	Thematic analysis		
Fuchsia Howard et al. 2014 Canada	8 rural community settings	To describe rural cancer survivors experiences accessing medical and supportive care post cancer treatment.	52 patients (2 groups) General Population: 41 patients (7 male, 34 female; mean age, 59) First Nation Population: 11 patients (4 male, 7 female; mean age 50)	Qualitative, descriptive Paper reports qualitative findings from mixed methods study	10	First nation sample size small Preponderance of females
			Mixed cancer type No cancer stage Cancer survivors Completed anticancer treatment within 60 months	Focus group interviews and individual semi-structured interviews		

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			'Some' participants accessed help-not further qualified			
			-	Content analysis		
Tan et al. 2014 Australia	Melanoma research and treatment centre	To identify psychosocial outcomes experienced by stage III melanoma patients and caregivers and to assess their coping responses.	19 patients (9 male, 10 female; mean age 58) 14 caregivers (4 males, 11 female, mean age 57)	Qualitative, descriptive and exploratory Cross-sectional	9	Caregivers predominately female. Authors cite risk of self-election bias.
			Melanoma Stage III Time from diagnosis: 0.6-3.1 years	Demographic questionnaire Semi-structured telephone interviews		
			Numbers of participants accessing help not described			
			Purposive	Thematic analysis		
Lambert et al. 2014 Australia	Gynaecology -oncology outpatient clinic	To better understand the preferences for psychosocial care of distressed women diagnosed with a gynaecologic cancer.	18 distressed‡ female patients (all female; age 30.0-77.5, mean age 53.9) ‡ scoring 4 or more on the DT	Qualitative, inductive Cross-sectional	10	Sample moderate to high distress. No demographic data for those who did not participate.
			Gynaecologic cancer Mixed cancer stage Time from diagnosis: average 20 months	Semi-structured interview (14 face to face; 4 telephone)		
			9 out of 18 participants accepted the invitation to see psychologist on the basis of their distress screen			
			-	Inductive thematic analysis		
Ekberg et al. 2014	Callers to five major	To examine callers' perceptions of using	32 cancer helpline callers (7 male, 25 female; 22 cancer	Qualitative , inductive Cross-sectional	9	Potential risk of self-selection bias

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UK	cancer helplines	a cancer helpline.	patients, 9 carers/ family members, 1 friend of a cancer patient).			
			Cancer type not described Cancer stage not described	In-depth semi-structured interviews (one-one telephone)		
			All participants were accessing helplines. Additional help accessed not described.			
			-	Inductive thematic analysis		
Olson 2014 Australia	Community setting (Australian Capital Territory)	To understand cancer carers' experiences and support preferences.	32 spousal carers (18 male, 14 female; age 30-89)	Qualitative, inductive Informed by sociologies of emotion and time Longitudinal	9	Risk of bias with sampling approach.
			Mixed cancer type Mixed cancer stage	Narrative and semi-structured interviews (face to face) conducted 6 months apart 26 individual interviews, 3 couples were interviewed together as each had been cancer patient and carer.		
			63% of participants had accessed support services (support groups, counselling +/- welfare).			
			Purposive and snowball	Thematic analysis (inductive coding)		
Wenger and Oliffe 2014 Canada	Cancer centres	How do men mobilise self-management and help-seeking strategies to manage their cancer.	30 patients (all male; age range 33-82, mean age, 59)	Qualitative, constructivist grounded theory approach Cross-sectional	9	Predominately white heterosexual men.
			Mixed cancer type No cancer stage Time from diagnosis: 0.5-10 years	Individual interviews (initial interviews open, later interviews semi-structured)		
			26 participants had accessed the cancer support centre-not further qualified			
			Theoretical	Constant comparative analysis		
McGrath	Leukaemia	To explore the	50 patients	Qualitative, exploratory	8	Limited description

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2014 Australia	Foundation of Queensland database	patient perspective on the value of a routine, annual follow-up telephone call from Leukaemia Foundation of Queensland support staff.	(26 male, 24 female)	Cross-sectional		of sample characteristics. Truncated description of research methods.
			Mixed haematological malignancies No cancer stage Haematology survivors (*One year post diagnosis*)	Open-ended interviews and one focus group		
			Numbers of participants accessing help not described			
			Purposive	Thematic		
Högberg et al.2013 Sweden	Adult haematology clinic University Hospital	To describe the prerequisites required for the provision and use of web-based communication for psychosocial support within a haematology clinic, from a patient and family perspective.	11 patients (6 male, 5 female; age 22-68) 6 family members (2 male, 4 female; age 38-57)	Qualitative, exploratory Cross-sectional	7	Not all respondent had used the web based communication system.
			Mixed haematological malignancies No cancer stage	Individual interviews (face to face)		
			All participants had access to web based psychosocial support			
			Strategical	Content analysis		
Shaw et al. 2013 Australia	Two metropolitan hospitals	To identify family caregivers' unmet supportive care needs and to investigate how they perceive their role after patients have undergone surgery for GI malignancy.	15 family caregivers (3 male, 12 female; mean age 50.6)	Qualitative Informed by grounded theory approach Longitudinal (3 weeks and 3 months post-surgery)	9	Predominately female sample. Only eight participants completed interview 2. Authors report an overrepresentation of family caregivers of poorer prognosis patients in interview 2.
			Family caregivers of patients undergoing surgical intervention for a newly diagnosed upper GI malignancy No cancer stage	Individual semi-structured interviews (telephone)		
			Numbers of participants accessing help not described			
			-	Modified constant comparison		
Gunn et	Rural cancer	To identify the key	17 patients	Qualitative	10	Definition of

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al. 2013 Australia	patients using supported accommodat-ion facilities	issues in psychosocial care provision and methods which might reduce barriers to service use, from the perspective of rural cancer patients.	(7 male, 10 female; age 24-72, mean 53)	Essentialist/realist methodological approach Cross-sectional		'psychosocial service use' very broad. Half in receipt of private health care. Sample predominately those >2yrs since diagnosis. Rural population. Authors cite risk of self-selection bias. Rural interviewer identify may have impacted on data gathering.
			Mixed cancer type Mixed cancer stage *No activity 9 Recurrence 1 Metastases 5 Do not know 2 (Self-reported by patient)* Variable time since diagnosis	Semi-structured interviews (face to face) Demographic questionnaire.		
			All participants had accessed help. Included telephone cancer helpline, supported accommodation facility and a psychiatrist but not further qualified			
			Purposive	Thematic analysis		
McGrath 2013 Australia	Leukaemia Foundation of Queensland database	To explore the experience of survivorship to inform supportive care provision and development.	50 patients (26 male, 24 female)	Qualitative, exploratory Cross-sectional	10	Limited description of sample demographics.
			Mixed haematological malignancies No cancer stage Haematology survivors *(Defined as one year post diagnosis)*	Individual open ended interviews (telephone) One focus group		
			Numbers of participants accessing help not described.			
			Purposive	Thematic analysis		
Harley et al. 2012	Five clinics at a cancer	To improve understanding of	56 patients (25 male, 31 female; age 50-84)	Qualitative, descriptive Cross-sectional	9	Experience of early chronic cancer

UK	centre	chronic cancer from the perspective of patients and their informal carers.	Mixed cancer type > 12months post-diagnosis of Chronic cancer *(Defined as active advanced or metastatic cancer that cannot be cured but where active anti-cancer treatments are available that can lead to symptom control, slow disease progression or prolong life)* Time from diagnosis: 13-155 months	Semi-structured interviews 17 patients attended interviews with informal caregiver		patients not included. Risk that patients with poorer health or those in the late stages of chronic cancer excluded. 17 patients were interview with informal caregivers present-this may have impacted on data collection.
			'Uncommon' for participants to access help except for a sub-sample of advanced gynaecological cancer patients who accessed a CNS led support group-not further qualified			
			Purposive	Framework analysis using a-priori themes		
Sinfield et al. 2012 UK	Urology clinics at two hospitals in different geographical areas in England	To explore the needs of carers of men with prostate cancer and to identify barriers and enablers to meeting these needs.	Thirty-four carers (all female, 23/34 were >55 years; 33 partners & 1 daughter)	Qualitative, exploratory Cross-sectional	9	All female sample. Single cancer type. Preponderance of partner/spousal carers.
			Prostate cancer Patients were receiving a range of cancer treatments including watchful waiting	Three focus groups (15 participants) 19 individual semi-structured interviews (13 face to face; 6 telephone)		
			Some participants had accessed help-not further qualified			
			Purposive	Framework analysis		
Skea et al. 2011 UK	Urological cancer centre	To examine uses of peer support among people living with a	26 patients (20 male, 6 female; age 37-80)	Qualitative evaluation Cross-sectional	8	Preponderance of male participants. Unable to ascertain
			Urological cancer	Individual semi-structured		

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			urological cancer. *Peer support included attendance at cancer centre, buddy support and online participation forum*	No cancer stage Variable time from diagnosis	interviews (telephone)		from sample description the total numbers of participants who did/did not participate in peer support.
				3 participants had accessed buddy support 7 participants had accessed on-line forums			
				-	Thematic analysis		
Corboy et.al. 2011 Australia	Medical specialist, oncology clinic or support group	To investigate perceived barriers to support service use among men living in rural Australia.	Sub-sample of 9 patients in qualitative component (all male; mean age, 69) 3 healthcare professionals	Mixed-method study Cross-sectional	9	All married male sample. Small sample size. Single cancer type. Rural population.
			Prostate Cancer (qualitative component) No cancer stage	Individual semi-structured interviews (face-face)		
			Numbers of participants in the qualitative sub-sample accessing help not described			
			-	Theoretically informed thematic analysis.		
Neumann et al. 2010 Germany	Psycho-oncology institution and affiliated hospital	Qualitative evaluation of psycho-oncology services (POS) focusing on the barriers to using these services.	21 patients (6 male, 15 female; age 18-80; 16 users and 5 non users of POS) 3 family members of POS users (2 male, 1 female, age 40-60) 10 HCPs (3 male, 7 female; age 25-50)	Qualitative evaluation Cross-sectional	9	Patient sample: predominately female and predominately in initial diagnosis phase. Small numbers of non service users. Small sample of family members. Participants from predominately urban location. Authors cite risk of self-selection bias.
			Mixed cancer type No cancer stage Time since diagnosis: 3-123 months	7 Focus groups (4 patient groups;1 family member group; 2 HCPs group) Individual interviews (3 patients POS non users and 2 HCPs)		
			Patient participants:16 users and 5 non users of POS Family member participants: numbers accessing help not			

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			described			
			Purposive	Thematic analysis and data interpretation using documentary methods		
Walton et al. 2010 New Zealand	Tertiary gynaecology service	To identify needs for supportive care in a sample of New Zealand women and to understand to what extent they feel their needs are being met by health services.	28 patients (all female; age 25-79)	Qualitative, exploratory Cross-sectional	10	All female sample. Predominately early stage.
			Gynaecologic cancer Mixed stage Time from diagnosis: < 5years	Individual unstructured interviews (face to face)		
			Numbers of participants accessing help not described			
			Purposive	Thematic analysis		
Maguire et al.2009 Germany	UK Military Defence Medical Welfare Service in Germany	To establish the nature and volume of supportive care received by British services personnel and their dependents who are stationed in Germany.	7 patients (sex/age not described) 6 informal carers (sex/age not described) 22 HCPs and military personnel	Qualitative, descriptive and exploratory, multi-perspective Cross-sectional	7	Predominance of HCP and military personnel. Limited description of sample. No exploration of power issues. Limited to the experience of army personnel cared for overseas.
			Mixed cancer type No cancer stage	Individual semi-structured interviews (all patients , 3 HCPs and 6 military personnel) Focus groups (HCPs and military personnel)		
			Numbers of participants accessing help not described			
			Purposive	Thematic analysis framed by a-priori themes		
Reeve et al. 2009 UK	Primary Care (Community)	To describe the impact of interactions with health care professionals	19 patients (8 male, 11 female; age 40-80s) 11 out of 18 'high risk' of depression[‡] ‡EDS –no cut off described.	Qualitative, phenomenographic approach Cross-sectional	10	Almost 50% of patients had respiratory cancer. Identity of researcher as a GP

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		revealed by people's accounts of living and dying with cancer; to explore reasons for the observed effects; and thus, to consider the implications for practice.	*A further 4 participants identified by clinical interview (not described).*			known to participants, may have impacted on data collection.
			Mixed cancer type Palliative	Individual semi-structured interviews (face to face)		
			Numbers of participants accessing help not described Purposive	Iterative thematic analysis		
Steele and Fitch 2007 Canada	Urban, outpatient regional cancer centre	To understand what motivates patients to ask or not ask for assistance when they have expressed need in specific areas.	34 patients (18 male,16 female; age 48-85, mean 65.2) 24 out of 34 participants reported feeling down or depressed‡ ‡*Study questionnaire –self report measure*	Qualitative, exploratory (Paper reports qualitative findings from mixed methods study)	8	Single cancer type.
			Lung cancer No cancer stage 15 patients were receiving treatment	Individual semi-structured interviews		
			Numbers of participants accessing help not described			
			-	Content and thematic analysis		
Clarke et al. 2006 UK	One hospital	To explore perceptions of available support services; second, preferences for source and type of support; and satisfaction with information and emotional support.	16 patients (6 male, 10 female; mean age melanoma 42.4, mean age breast 51.2)	Qualitative, exploratory Cross-sectional	9	Single cancer types. Authors state that data may not be saturated.
			Melanoma (11) and breast (5) No cancer stage Patients in receipt of anti-cancer treatment	Individual semi-structured interview		
			Numbers of participants accessing help not described			

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			-	Thematic analysis		
Docherty 2004 UK	3 cancer support groups	To understand the components of the group facilitating the experience of support, member satisfaction and the relationship between this and the quality of service experienced by patients during their cancer care.	27 support group members (18 patients: 4 males, 14 females; 6 carers/marital partners: 4 males, 2 females; 1 nurse; female. All participants; age 43–78) Variable time since diagnosis	Qualitative, exploratory Cross-sectional	7	Preponderance of females. Preponderance of breast cancer. Inclusion of sole HCP in one focus may have impacted on data collection and exploration of power within focus groups.
			Mixed cancer type No cancer stage	3 focus groups Brief interview guide		
			All participants were accessing cancer support groups. Additional help accessed not described.			
			-	Process of initial, axial and selective coding to develop categories and themes		

DT: Distress Thermometer (Holland JC, Andersen B, Breitbart WS, et al. 2013)
EDS: Edinburgh Depression Scale (Lloyd- Williams, Friedman & Rudd, 2000).
HADS: Hospital Anxiety and Depression Scale (Zigmond & Snaith 1983; Bjelland et al. 2002)

CASP qualitative checklist criteria: 1.Was there a clear statement of the aims? 2. Is a qualitative methodology appropriate? 3. Was the research design appropriate to address the aims of the research? 4. Was the recruitment strategy appropriate to the aims of the research? 5. Was the data collected in a way that addressed the research issue? 6. Has the relationship between researcher and participants been adequately considered? 7. Have ethical issues been taken into consideration? 8. Was the data analysis sufficiently rigorous? 9. Is there a clear statement of findings? 10. How valuable is the research?

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Table 2. Papers contributing to the development of themes

	Attaining normality- the normality paradox		Being Emotionally Literate		Perceptions of help				Needs-Support gap
	Maintaining Normality	*Seeking Normality*	*Emotional space*	*Emotional disclosure*	*Limited help*	*Limited benefits*	*Perceived risks*	*Perceived benefits*	
Pascal et al. 2016	x		x	x	x	x	x	x	X
Beaver et al. 2016	x	x	x	x	x	x	x	x	x
Braamse et al. 2016	x	x	x	x	x				x
Reagan et al. 2015b	x	x		x		x		x	x
Brown et al. 2015	x			x	x	x	x	x	x
Stapleton et al. 2015	x			x		x		x	x
Bird et al. 2015	x	x		x	x		x	x	x
Stamataki et al. 2015	x			x	x			x	x
Mosher et al. 2015¶	x			x	x	x	x	x	x
Pascal et al. 2015	x	x		x	x	x	x	x	x
Fuchsia Howard et al. 2014			x	x	x	x	x	x	x
Tan et al. 2014	x		x	x					x
Lambert et al. 2014¶	x	x	x	x		x		x	x
Ekberg et al. 2014				x	x		x	x	x
Olson et al. 2014	x	x	x	x	x	x	x	x	x
Wenger and Oliffe 2014	x	x	x	x	x	x	x	x	x
McGrath 2014		x					x	x	x
Högberg et al. 2013	x	x	x	x	x	x			x
Shaw et al. 2013	x		x	x					x
Gunn et al. 2013	x	x	x	x	x	x	x	x	x
McGrath 2013	x	x	x	x	x		x	x	x
Harley et al. 2012	x		x	x	x	x	x	x	x
Sinfield et al. 2012	x	x		x	x	x	x		x
Skea et al. 2011	x	x		x			x	x	x
Corboy et al. 2011	x		x	x	x	x	x	x	x
Neumann et al. 2010	x	x	x	x	x	x	x		

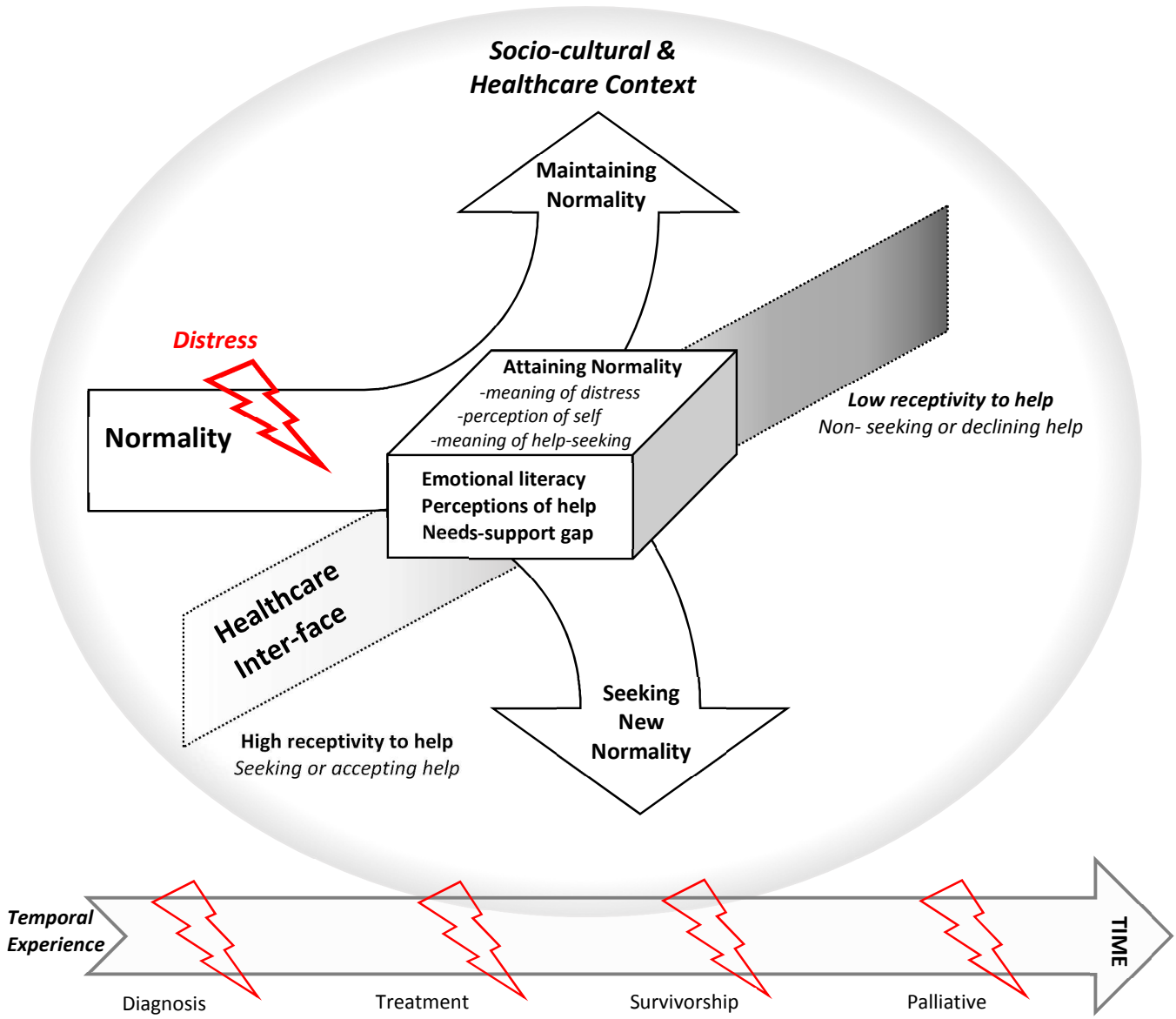|									
Walton et al. 2010		x	x	x	x	x		x	
Maguire et al. 2009	x			x	x	x	x	x	x
Reeve et al. 2009[¶]	x			x				x	
Steele et al. 2008[¶]	x	x	x	x	x	x		x	x
Clarke et al. 2006	x			x	x				x
Docherty et al. 2004		x		x		x		x	x

[¶]Indicates studies which were drawn from predominately distressed populations

Key:	Patient-only	Caregiver-only	Multi-perspective

Figure 2. '*Attaining Normality*': seeking, accepting and declining help for emotional distress in cancer

Socio-cultural & Healthcare Context

Maintaining Normality

Distress

Normality

Attaining Normality
-meaning of distress
-perception of self
-meaning of help-seeking

**Emotional literacy
Perceptions of help
Needs-support gap**

Low receptivity to help
Non- seeking or declining help

Healthcare Inter-face

Seeking New Normality

High receptivity to help
Seeking or accepting help

Temporal Experience

Diagnosis

Treatment

Survivorship

Palliative

TIME

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Appendix 1. Search terms used and databases searched

Search strategy
S1   distress OR emotion* OR psycho* OR anxiety OR depress* OR mental health
S2   cancer OR oncol* OR malig* OR palliative OR end of life OR hospice
S3   help seeking OR help-seeking OR desire for help OR desir* help OR request* help OR want* help OR need* help OR wish* help OR seek* help OR accept* help OR declin* help OR reject* help OR refu* help OR uptake of help OR preference* for help OR help preference*
S4   desir* referral* OR request* referral* OR want* referral* OR wanting a referral OR wish* referral* OR wishing a referral OR wish for referral OR referral wish OR accept* referral* OR accepting a referral OR declin* referral* OR declining a referral OR reject* referral* OR reject a referral OR refu* referral* OR refuse a referral OR referral* uptake OR uptake of referral* OR preference* for referral* OR referral preference*
S5   use of service* OR service* use OR uptake of service* OR service* uptake OR utili* of service* OR service* utili* OR preference* for service* OR service* preference*
S6   desir* support OR request* support OR want* support OR wish* support OR accept* support OR declin* support OR refu* support OR reject* support OR need* support OR uptake of support OR support uptake OR preference* for support OR support preference*
S7   desir* treatment* OR request* treatment* OR want* treatment* OR wish* treatment* OR accept* treatment* OR declin* treatment* OR refu* treatment* OR reject* treatment* OR need* treatment* OR uptake of treatment* OR treatment* uptake OR preference for treatment* OR treatment* preference*
S8   desir* intervention* OR request* intervention* OR want* intervention* OR wish* intervention* OR accept* intervention* OR declin* intervention* OR refu* intervention* OR reject* intervention* OR need* intervention* OR uptake of intervention* OR intervention* uptake OR preference* for intervention* OR intervention preference*
S9   psychological care OR psychosocial care OR supportive care
S10   S1 AND S2 AND S3
S11   S1 AND S2 AND S4
S12   S1 AND S2 AND S5
S13   S1 AND S2 AND S6
S14   S1 AND S2 AND S7
S15   S1 AND S2 AND S8
S16   S1 AND S2 AND S9
S17   S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16
Databases searched: MEDLINE, CINAHL, PsycINFO and Behavioural Sciences collections via Knowledge Network, NHS Scotland