Establishing Best Practices in Online Cancer Support Groups: A Realist Review

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INTRODUCTION

Online Support Groups (OSGs) are virtual social spaces where people with a common condition come together to get and give information and support. (1)

- OSGs offer a convenient way for cancer patients and survivors to obtain relevant information and support. (2)
- Not all OSGs are helpful, and some may increase distress (3).
- There is a lack of clear evidence on the effects of OSGs, along with how and why they work. (4)
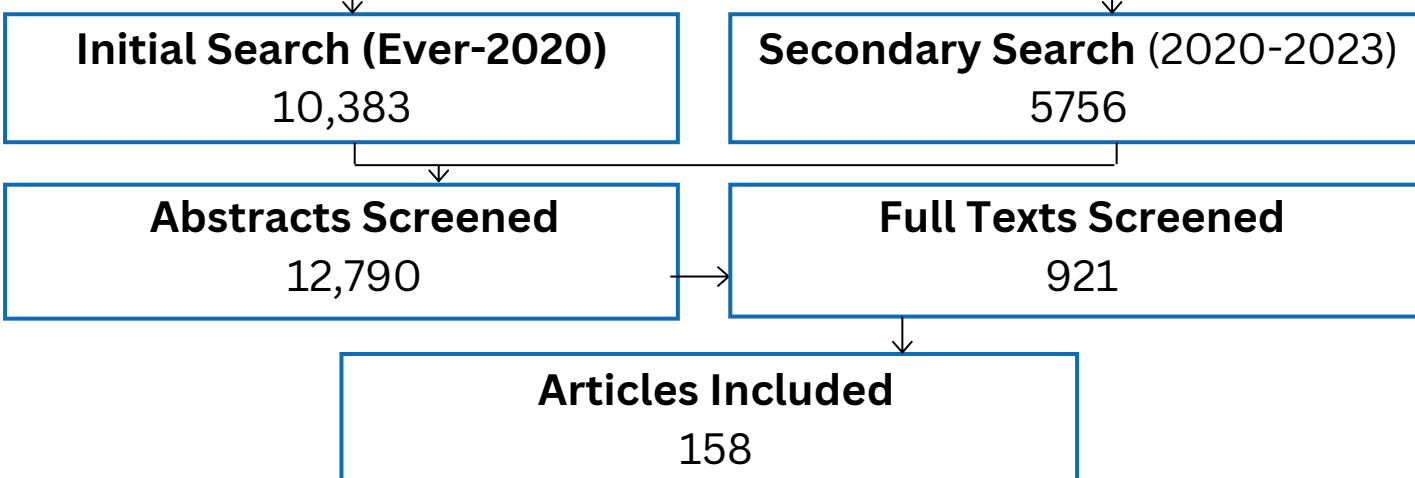
RESEARCH AIMS

1. To understand why, for whom, and in what contexts OSGs work or do not work for cancer patients and survivors
2. To provide recommendations on how to optimize cancer OSGs to meet the needs of users

METHODS

A realist review was conducted to examine how underlying processes of OSGs in specific circumstances interact to produce outcomes. Pawson's (5) and RAMESES (6) guidelines were followed.

Step 1: Develop an initial program theory based on search of existing theories and stakeholder consultation
Step 2: Conduct a systematic review of the literature
Step 3: Select and appraise studies
Step 4: Extract and organize data into conceptual buckets
Step 5: Conduct a rigorous iterative analysis to differentiate into Context, Mechanism, Outcome Configurations (CMOCs)
Step 6: Refine the program theory and hold a stakeholder consultation to share and discuss findings

Data Sources: Medline, EMBASE, The Cochrane Database of Systematic Reviews, The Cochrane Central Register of Controlled Trials, Ovid EmCare Nursing, PyschINFO (all via Ovid), CINAHL (Ebscohost), Scopus (Elsevier), Clinical Trial registries (ClinicalTrials.Gov & WHO ICTRP), Dissertations (ProQuest Digital Dissertations International) & Books/Chapters (University of Toronto OneSearch)

Initial Search (Ever-2020) 10,383	Secondary Search (2020-2023) 5756
Abstracts Screened 12,790	Full Texts Screened 921
Articles Included 158	

MOTIVATION

Attitudes

Motivation to use OSGs is influenced by perceptions of their usefulness trustworthiness, and ease of use. This is Influenced by:
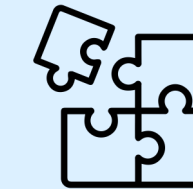- socioeconomic status
- societal/cultural norms
- time since treatment

Need/Fit

Motivation to use OSGs is influenced by a person's needs, and how well OSGs fit them. This includes:
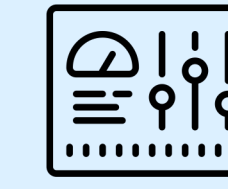- health status
- coping styles
- socioeconomic status
- social support
- societal/cultural norms

Control Beliefs

Motivation to use OSGs is influenced by whether users can control interactions with others. This includes:
- when/where they access
- when/how they contribute
- what they disclose and how
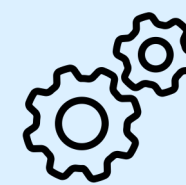- when/how they disengage

USE

Technology Features

Technology features influence use and may lead to differing outcomes depending on:
- response time from others
- visual cues/physical closeness
- privacy and anonymity

Group Dynamics

Group norms influence user interactions and may lead to differing outcomes, depending on:
- sense of connection between users
- safe, open, and welcoming environment
- supportive moderators

Content

The content of posts have a strong impact on positive or negative outcomes. This includes:
- the ability to express emotions (positive and negative) and receive support
- encouragement of cognitive processing to reframe the cancer experience and enhance understanding
- use of humor to provide a distraction and facilitate emotional expression

OUTCOMES

Social Support

- **Emotional Support** - helps people feel heard, cared for, understood, and accepted
- **Informational Support** - helps people feel knowledgeable about what to expect and how to meet their own needs
- **Validation Support** - helps people judge the accuracy of their thoughts, feelings, and behaviours, and feel normal
- **Altruistic Support** - boosts self-esteem and confidence

Psychosocial Wellbeing

When OSGs work well and meet user needs, users obtain social support which improves psychosocial wellbeing including:
- reduced distress
- reduced feelings of Isolation
- greater empowerment
- greater self-Esteem

EXAMPLE CMOCS and QUOTES

MOTIVATION (NEED/FIT): People with avoidant coping styles (C) may be less likely to use OSGs or less likely to benefit (O) because they may feel distressed by others expressing their emotions in the OSGs (M)

USE (CONTENT): When OSG users express negative emotions and thoughts in an OSG (C) they experience stress relief (O) because writing about a stressful event allows one to process and learn from one's emotions (M)

OUTCOMES: When an OSG member receives supportive comments (e.g., empathetic, compassionate, encourage and/or expressions of solidarity responses) (C), they feel emotionally supported (O), because know other people care about them (M)

CONCLUSION

- OSGs can be an effective source of support for cancer patients that can improve psychosocial wellbeing.
- Outcomes (i.e., social support) depend on contexts (i.e., motivation, needs) and mechanisms (i.e., trust, control) that impact how well OSGs meet user needs .

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